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Understanding Patient, Family Caregiver and Health Care Team Member ACO Experience

Background

This research sought to understand how patients, their family caregivers and members of the health care team experience receiving or providing care through an Accountable Care Organization (ACO) model. The goal is to use the learnings to build a foundation for educating and engaging the patient and consumer advocacy community, policymakers and others about the ACO experience and its potential to improve the care experience, outcomes and efficiency.

Research: The research was conducted by the [American Heart Association](#), approved by the [Heartland Institutional Review Board](#), Project No. 021224-534, and funded through [Arnold Ventures](#).

Expert Panel: An advisory expert panel of 15 members was convened with representatives from consumer and patient organizations as well as multi-stakeholder groups.¹ In addition, input on the research from other organizations was also sought and provided to ensure a wide array of views and issues were captured.²

Patient Priority Issue Identification: The research was informed by a literature review of academic and gray literature that addressed *patient- or person-centered care* and *patient engagement or patient experience*. A list of resources is provided in Exhibit A. The following patient priority areas emerged, many of which overlap and were incorporated into the key informant questionnaires:

- *Care that is respectful of and responsive to patients' needs and values.* Does the patient feel seen and heard as a person? Patients are seen in their context and as a person rather than an ailment or condition. Includes cultural competence, shared decision-making on goals of care and treatment options. Patients receive responsive and compassionate services, which are essential to building trust.

¹ Expert panel members included representatives from Accountable for Health, American Heart Association, Coalition to Transform Advanced Care, Community Catalyst, Duke-Margolis Institute for Health Policy, Families USA, Health Care Transformation Task Force, National Association of Accountable Care Organizations, National Association of Community Health Centers, National Health Council, National Kidney Foundation, National Partnership for Women and Families, Primary Care Collaborative, The ARC, United States of Care.

² Other organizations that provided input include Centers for Medicare and Medicaid Services Innovation Center, Hydrocephalus Association, International Consortium for Health Outcomes Measurement, National Organization for Rare Disorders, Patient-Centered Outcomes Research Institute, The Journal of Patient Experience, World Economic Forum.

- *Effective bi- or multi-directional communication.* How effective is communication between patients, their caregivers and all members of the care team? This includes culturally competent communication, shared decision making, gaining access to critical information and ensuring understanding of treatment options (physical, emotional, social). Effective communication is essential to building trust.
- *Whole-person care.* Are physical, mental and non-medical drivers of health addressed?
- *Seamless, coordinated, longitudinal care.* Is the care well-coordinated and integrated? This includes care and social support navigation, robust medical information sharing, case and care management and coordination. Also, it includes a usual source of care through a primary care provider and a care manager or navigator.
- *Knowledgeable and competent practitioners/care team members.* Does the patient and family caregiver trust the knowledge, skills and abilities of the health care team members? Do they rely primarily on their health care team members for information about their conditions, options, referrals, etc.?
- *Timely access to care and support.* Are patients seen and their needs met in a timely manner? This includes scheduling, minimal wait times, having enough time with providers and not feeling rushed, accessible locations and convenience.
- *Reasonable costs and cost transparency.* Are attempts made to incorporate affordability into decision making when possible? Patients and their family caregivers should be consulted about costs and there should be no surprise bills.
- *Outcomes.* Have the patient's goals of care been met? Has care been delivered in a safe and effective manner? Have gaps in care been addressed? What is the clinical quality of the care provided?

Key Informant Interviews: Two separate interview guides were created, one for patients and/or their family caregivers and one for health care team members. The guide for patients and caregivers contained 33 questions and looked at the patient's background and goals of care, care team interactions and care coordination/management, access and affordability, person-centeredness and communications and general impressions. The health care team member guide had 47 questions and explored the following areas: clinical background; health care team communication, coordination and collaboration; health equity; access and affordability; outcomes; patient engagement; practice, skills and culture; and general impressions. The interview guides can be found in Exhibits B and C. Between 25 and 30 key informant interviews of medically complex patients and/or their family caregivers and members of the health care team who receive or provide care through an ACO model were expected.

Confidentiality and Informed Consent: The research protocols including those on confidentiality and informed consent were reviewed and approved by Heartland IRB. To encourage open and honest answers, the confidentiality of study participants' identities and responses are protected. An informed consent form about the research was provided ahead of each interview. At the beginning of each interview, study

participants were asked if they had reviewed the form, if they had any questions and if they gave their informed consent to be interviewed and to have the interview recorded. The informed consent information can be found in the interview guides in Exhibits A and B. All study participants consented to the interview and to the interview being recorded to assist with transcription. In addition, study participants were informed that in public facing documents, quotes would be used but names would not be provided. To distinguish between study participants in public facing documents, roles and/or the state where health care is received or delivered are used.

Recruitment: Recruitment was done through health care organizations participating in ACO models because most patients are not aware that they are in an ACO. Recruitment methods complied with privacy laws and were approved by the IRB. A \$100 stipend (Visa gift card) was emailed or sent to study participants upon completion of the interview. Recruitment was extremely challenging; and many ACOs declined to participate due to factors such as the Change Healthcare data breach, other competing priorities, our request for higher acuity patients and overworked front-line staff.

Interviews: Interviews were conducted virtually (Microsoft Teams) or over the phone. Most but not all were recorded using Microsoft Teams to assist with transcription. While twenty-nine interviews were conducted, only 27 were included (one patient was not in an ACO or other value-based arrangement and another was an employee of the health care organization). There were 15 health care team member interviews and 12 patient and/or family caregiver interviews (nine were with the patient only; two were with the patient and his/her family caregiver and one was with the caregiver only).

Methods/Data Analysis: Using interviewer notes and cleaned transcripts, each interview was written into a narrative by the principal investigator or the research assistant. Those narratives were then used for data analysis. Coding was done by hand by the principal investigator, although ChatGPT was also used for comparison purposes. The patient and caregiver interviews were coded and analyzed separately from the health care team interviews given the different focus on receiving versus providing care.

Limitations: This research did not include a comparison group of study participants practicing or receiving care under traditional fee for service. Given the limited number of interviews, the findings are not generalizable, although they are useful for the intended purpose of demonstrating what care can be like under the ACO model. The use of a single coder in data analysis could result in single coder bias. To counter this as much as possible, *in vivo* quotes are used frequently to demonstrate support for the themes.

Findings

Overall, the research suggests that the care received and provided through ACOs is better for patients, caregivers and health care team members, raising the expectations of our health care system to enable optimal health and well-being for those served by the system and to provide a better work experience for health care professionals on the

front lines. This does not mean that the level of care or professional satisfaction was identical or perfect across ACOs—it was not. However, the shared view of all study participants was that it is an improvement over traditional fee for service.

Patients and Caregivers

Patients and family caregiver interviews included nine with the patient only, two with the patient and his/her spouse/family caregiver and one with the patient's spouse/family caregiver only. All patients were medically complex with multiple serious conditions that interfered with their health and quality of life, including conditions such as liver transplants, aortic valve replacements, amyloidosis, cancer, congestive heart failure, chronic obstructive pulmonary disease, diabetes, obesity, etc. The ages of study participants ranged from 36 to over 75. Those who were under 65 were on Medicare due to disability and were also on Medicaid. Payers included Medicare, Medicare Advantage, Medicaid and Federal Employee Program, with all health care provider organizations in contractual arrangements with accountability for cost and quality of care. Rural, suburban and urban geographies were represented. Race/ethnicity was captured inconsistently although Black/African American study participants are likely overrepresented and white, Hispanic and others are under-represented based on U.S. population percentages.

Each interview was written up into a narrative for coding by either the principal investigator or the research assistant. The narrative was entered into ChatGPT first for summarization and then again for a more simplified and understandable description. A brief overview of each patient and/or family caregiver as well as the technical summarization and the simplified description of each narrative are provided in Exhibit D.

The overarching message from the patient and family caregiver interviews is that care provided by ACOs is better for patients.

Better Care and Support

While the care and services provided across the ACOs varied, several common themes emerged, indicating that patients in ACOs receive better care and support through:

- A dedicated primary care relationship—all study participants had a relationship with a primary care provider (PCP) and those relationships were overwhelmingly positive.
 - According to P13's wife/caregiver, C3: "[P13's PCP] is very respectful and if he isn't sure about something, he researches it and gets back to you. He is exceptional."
 - P3 started seeing her current PCP after she was diagnosed with cancer. After she had her first visit, P3 said, "[The PCP] spent the whole next weekend going through my file. She has been wonderful. She is outstanding. The staff is outstanding. I've had no problems and have always felt well taken care of." P3 feels that she is heard and understood, that her providers put her best interests

- first and that her PCP sees her as a person, adding: "She definitely sees me as person and she understands what is important to me."
- When asked what he likes best about his care, P10 talks fondly of his PCP: "It's always good to see her. We ask about each other's families. We have a personal relationship and are on a first name basis. Our relationship couldn't be any better."
 - A team of health care professionals who provide enhanced care and support.
 - According to P8, "I have the best team I can get. The nurses are the go-between me and my doctor. I coordinate with the hospital van to commute here to get me to the appointments. It is the best treatment and doctor. If I am due to see two doctors in the same month, they coordinate the appointments at the same point."
 - P12 shared that he has been pleased with his physicians but especially his PCP, Dr D, who he credits with keeping him on track. C3, his wife and caregiver, mentioned an "ACO program" that started about 3 years ago through his PCP. She recalled that P12 was going in and out of heart failure on a regular basis and the introduction of the care manager through his PCP's office made all the difference and provided excellent care: "Without the care manager, he might not have been able to do it. The care manager is an extremely important part of his care team. It is an excellent program."
 - P9 says: "I love how supportive and how caring they are even when they didn't know me. I've had the greatest experience from them, they've gone over the top."
 - Improved access to care and support including assistance with emergent or urgent issues, timely responses and connection to needed resources.
 - When a health concern arises, P1 and C3 call their care manager, who will either answer the phone or call them right back. "When we have extra things that come up like a UTI or getting sick with the flu, we call our care manager and she gets us in and gets us the help we need and does it immediately. She finds someone within the system to help us." In addition to calling their care manager, they also can call their PCP's nurse at any time including after hours, so they feel well connected, but they generally "call [the care manager's] number and leave a message and she gets right back and then double checks to see if they need anything and make sure they are doing okay."
 - P2 feels that she is able to see and/or talk to her health care providers when needed. She just "calls and has her needs addressed." After a hospitalization, "they are good with getting me in to see them. They make it easy."
 - P3 praised her PCP, Dr P, saying the care she receives is "outstanding, it is great. I have a chronic care manager, so I don't have to go through a nurse and she provides an instant response, so I don't have to wait for someone to call me back."
 - Enhanced patient engagement, which includes more time spent with patients and co-developed care plans.

- P2 shared that “sometimes, I’m in there for an hour. I never feel rushed and I get the whole 9 yards.”
- Reflecting on her healthcare journey, P12 appreciates the personalized attention: “They make me feel like they are concerned about me.”
- P4’s health care providers understand what is important to her and involve her in the development of her care plan.
- P13 and C3, referring to P13’s PCP, agree: “He knows what is important to me and asks about my goals.” C3 noted that Dr D includes her in the decision-making process as well.
- Trusting relationships that make patients feel heard, understood and valued as a person, with most patients reporting that they primarily relied on their providers for referrals and information about their medical conditions.
 - P9 shared: “This year has been a game changer with the doctors because they really do care about you. The nurse practitioner cared, understood and listened to me, and that is how I was connected to the social worker. It changed my dynamic. I wish everyone could experience the care I had. This was a blessing in disguise. They really gave me life. I feel way better than ever.”
 - P3 noted: “They treat me as an individual, as a person, and not an ailment. They are very hands-on and explain everything well. And I love the chronic care manager because she is great and responsive.”
 - “I feel like my health care team is supportive,” P12 said. “I’m comfortable with them and trust their recommendations.”
 - P2 says she relies exclusively on her providers for information about her conditions and treatments. When asked what she likes best about the care she receives, P2 said: “I feel like they understand what I am talking about.” She had no suggestions for improvement: “It is wonderful, it can’t get any better.”
 - When choosing a specialist, P1 relies on the recommendations of his PCP. P1 and his caregiver, C1, also rely exclusively on his health care team for information about P1’s conditions.
- Improved communication, access and coordination with patients and/or family caregivers and other health care providers.
 - According to C3, a caregiver for her husband: “You can’t get any better than this. I wouldn’t trade any of his doctors because I know them personally and if you have got a question, you can ask them.”
 - When asked what they liked best about the care he receives, P1 said, “the way we are getting care with the care manager, we get more immediate responses because the doctors’ appointment schedule is so far out, but when you call with a need, they make sure it is taken care of. It didn’t used to be that way.”
 - P9 shared that the team members spend enough time with her and she never feels rushed. “They spend as much time with me as I need. They all do that. They’ve been great.” P9 is also able to get up with the team when needed through a mobile app, which she describes as “pretty easy,” and someone will call back in a timely manner (at least the next business day). She is seen in a

manner that is convenient for her and she frequently utilizes telehealth for non-routine visits. The social worker also visited her at her home.

- A more holistic approach to care that addresses physical, mental and emotional health as well as non-medical barriers to health such as access to healthy food, transportation, housing-related issues, financial assistance and other services that contribute to improved health and enhanced quality of life.
 - According to P4, "My experiences have been very good especially when compared to friends who don't have this level of care and don't really know who they are going to. The great thing about this organization is that someone is responsible for you, medically, physically, mentally and financially, so that makes it all work for me."
 - In addition to her physical ailments, P3 is asked about her mental and emotional health and currently sees her psychiatric NP twice a week. She is very satisfied with these interactions. P3 is also asked about health-related social needs by her PCP, therapist and social worker, and they have been able to connect her to resources such as the Delaware Food Pharmacy and to transportation, when needed.
 - P10 is asked about this mental and emotional needs by his PCP and he has been to counseling. He also is asked about non-medical issues such as food, housing, etc., and is provided gift cards to help with expenses.

Receiving care through an ACO compared to Traditional Fee for Service:

Patients and caregivers shared why care, services and supports provided through an ACO is better than traditional fee for service:

- "A year ago when he was first diagnosed with congenital heart failure, his care manager got him into an extended care clinic and those doctors were so good. They actually helped get proper care for him and it has been a blessing. I think going to [an ACO], others in our age group don't have it. It is really wonderful. They keep you out of the emergency room where you stay and stay and stay." – P1 and his wife, C3, North Carolina
- "This year has been a game changer with the doctors because they really do care about you. The nurse practitioner cared, understood and listened to me and that is how I was connected to the social worker. It changed my dynamic. I wish everyone could experience the care I had. This was a blessing in disguise. They really gave me life. I feel way better than ever." – P9, Pennsylvania
- "My experience has been very good with [an ACO]. Once they know the drill, they work together and make sure I have food and that I am bathed." While her children take her to her health care appointments, she has a care manager who checks on her regularly and with whom she is in frequent contact. – P2, North Carolina
- "The care I get [through the ACO] is outstanding, it is great. I have a chronic care manager, so I don't have to go through a nurse, and she provides an instant response, so I don't have to wait for someone to call me back." – P3, Delaware

- "My experiences have been very positive. I am a real fan of my ACO because they are organized and the docs are terrific. I don't need to look for a doc because they will provide them. They also have a robust electronic health record and it is easy to message the care team and to make appointments. On a scale of 1 to 10, it's a 10." – P4, Washington, DC
- "The introduction of the care manager through the ACO program at his primary care physician's office made all the difference and provided excellent care. Without the care manager, GG might not have been able to do it. The care manager is an extremely important part of his care team. It is an excellent program." – P13, caregiver to husband, C3, Pennsylvania
- "The nurses are the go-between me and my doctor. I coordinate with the hospital van to commute here to get me to the appointments. It is the best treatment and doctor. If I am due to see two doctors in the same month, they coordinate the appointments at the same point." – P8, West Virginia
- "I have a care manager who I talk to once or twice a month who helps connect me to needed resources." – P10, Maryland
- "I feel like my health care team is supportive. I'm comfortable with them and trust their recommendations." – P7, Virginia
- "I see my new primary doctor, Dr. C, who seems to be fantastic. They make me feel like they are concerned about me." – P12, Maryland
- "There is a program with [the ACO] in which every month they give us gift cards to buy food with. They have all kinds of other food programs. The food bank drops food every week." – C2, caregiver, Maryland

Health Care Team Members

The health care team members interviewed included: four primary care physicians, one specialty physician, one advanced practice provider (nurse practitioner), four nurse care managers/navigators, two social workers, two community health workers and one pharmacist. The combined experience of all health care team members interviewed was over 250 years, with over 80 years of combined experience in ACO arrangements. The ACOs represented were from different areas across the country and participated in Original Medicare and/or Medicare Advantage ACO programs with many also having Medicaid and commercial contracts. While the ACOs were of varying sizes with different capabilities, services and populations, several common themes emerged.³

Better for Patients

All health care team members interviewed unanimously agreed that the care provided to patients, especially those who have multiple health-related issues, was better because of the extra time, attention and support provided through the ACO, leading to improved outcomes.

- “The impact of the ACO on quality of care has been phenomenal, exponential. I don’t know how we existed before. I would not be a physician like I am without it.” – primary care physician, Delaware
- “Providing care under the ACO is better for patients because of the emphasis on preventive care, patient education, meeting patients where they are, closing gaps in care, connecting patients to needed resources and freeing up doctor’s time to focus on those patients who need the most attention, which in turn improves the quality of care.” – community health worker, Arizona
- “Interdisciplinary collaboration is a key aspect of the care provided. We are more proactive about screenings. We are catching things early and getting patients the care they need before they know they need it. We are implementing what improves health. We seek control before they slide.” – nurse practitioner, Pennsylvania

This enhanced level of access to care and support is made possible by:

- Having a regular source of care through a primary care physician or advanced practice provider such as a physician assistant/associate or a nurse practitioner.
 - “In the ACO, patients have a regular source of care through a PCP and the health navigators go directly to the PCP with any needs or concerns.” – nurse care manager, North Carolina
 - “We work with everyone to get a PCP.” – social worker, Ohio

³ While all health care team member study participants were asked how they monitor health outcomes across different populations, this was interpreted differently based on location of the ACO and where the individual sat in the organizational structure. Larger ACOs in more urban areas with significant minority populations and those who also had management roles tended to have more awareness of racial and ethnic disparities and efforts to monitor and address those disparities than other study participants, making it difficult for health equity approaches to be a stand-alone theme.

- A multi-disciplinary team-based approach to care, which brings different areas of focus and allows extra attention, care and support to be deployed to patients with greater health needs.
 - “It is better because we have an entire team focused on improving quality of care and multiple resources to assist patients and more open communication. Providers cannot know everything going on outside of the office and the ACO provides that information. It has improved patients’ quality of care.” – pharmacist, Ohio
 - “Patients in an ACO get better care because there is an interdisciplinary team working together to help ensure patients get what they need.” – community health worker, Arizona
- A whole-person approach to care, which means the health care team can look at all factors that impact a patient’s health and well-being and connect them to needed health-related care, resources and assistance.
 - “It is better because it is our mission to provide more comprehensive care and follow through and connect them with services they need and communicate with physicians. At the end of day, we need to make sure a person is taken care of body, mind and soul. Also, it helps the whole family with getting resources.” – community health worker, Arizona
 - “The care provided by the model is superior; quality of care is significantly higher because the model takes a holistic approach, considering the person as a whole rather than as separate parts.” – social worker, Ohio
- Enhanced patient engagement and education, which means that there is a greater emphasis on effective communication, building trust and understanding the patient as a person through motivational interviewing, shared decision making, regular assessments and care plan development. This also includes greater attention to patient populations and communities that have historically had access challenges and connecting them to resources and assistance when needed.
 - Effective communication
 - “To improve patient understanding, health navigators talk to patients in layman terms, use repeat back techniques and let them ask questions.” – nurse care manager, North Carolina
 - “You have to tailor the communication to their needs whether that means driving around looking for a homeless patient, using text messaging when preferred, using the telephone for the elderly, or home visits, etc. Also finding ways to help dementia patients remember things. We try to meet the patients where they are. We do a lot of listening to what they need and are constantly open to what they need to make their health accessible to them. Need to ask and understand each person’s preferences and just listen to what people are telling me.” – community health worker, Arizona
 - “The ACO has had a positive influence on communication and coordination among members of the health care team and it has helped to strengthen trust in team members and if you message them about a concern, the MDs

- know the patients we work with are sicker, so they prioritize that patient. We work more together. They've seen that what we do is effective, so it builds that trust. When patients need something, my role is to make sure that they get what they need and to troubleshoot any problems." – nurse care manager, North Carolina
- Building trust
 - "The biggest thing is empathy. It seems basic but you really need to sit with patients and understand the barriers. You must have good communication skills to talk to the patients and care team members frequently and comfortably" – pharmacist, Ohio
 - "Motivational interviewing, cultural competency training, believing in the mind, body, spirit connection and being respectful of all beliefs and religions are competencies or skills that help health care professionals practicing in ACO be more effective." community health worker, Arizona
 - Understanding the patient as a person
 - "As a community health worker, I must be compassionate and empathetic because I take on a lot of responsibility for their social and medical needs to provide the right referrals. They just want to be listened to. We do a lot of listening to what they need and are constantly open to what they need to make their health accessible to them. Need to ask and understand each person's preferences and just listen to what people are telling me." – community health worker, Arizona
 - "The biggest thing is empathy. It seems basic but you really need to sit with patients and understand the barriers." – pharmacist, Ohio
 - "We need to be respectful of their wants and needs. We respect their preferred communication needs. We understand that they are a person and it is their right to make decisions even if it is a bad one. We are treating them as individuals and respecting their wishes." – social worker, Ohio
 - Shared decision making
 - "Also essential is the ability to engage in motivational interviewing and shared decision making." – primary care physician, Delaware
 - "We have a comprehensive assessment for chronic care management, which includes a care plan tailored to the patient's chronic conditions, focusing on the whole-person. Patients are fully engaged with the care plan, which includes a self-rating of their health and a self-identified goal. The assessment also includes a medication review." – social worker, Ohio
 - Regularity of assessments
 - "The frequency of physical needs assessments is variable, depending on patient needs and care plans. Mental, emotional and social needs are assessed during all encounters with patients." – social worker, Massachusetts
 - "Physical needs are assessed all the time, whenever they come in. Mental and emotional needs are assessed as frequently as possible, ideally during every visit. Social needs assessments have only recently started, but we previously

- connected patients to social resources when known.” – primary care physician, Texas
- Care Plan Development
 - “We have a comprehensive assessment for chronic care management, which includes a care plan tailored to the patient's chronic conditions, focusing on the whole-person. Patients are fully engaged with the care plan, which includes a self-rating of their health and a self-identified goal. The assessment also includes a medication review.” – social worker, Ohio
 - “Individual care plans, particularly for care management patients, are important and are developed with patients during visits.” – primary care physician, Kansas
 - Underserved populations and communities
 - “One way the ACO tries to address inequities is ensuring that they have employees who are from the communities they serve. For example, in Texas and Arizona, all the CHWs are fluent in Spanish and English and most of the CHWs are Hispanic and thus are also familiar with the culture.” – community health worker, Arizona
 - “There is a big focus on the community we serve, and [putting] patient’s first, and making sure they get what they need.” – specialist physician, Indiana
 - “ACOs are more proactive rather than reactive. The data provided by ACOs allows us to address gaps in care more effectively.” – primary care physician, Kansas
 - “We can monitor outcomes through the dashboard that marries claims and EHR data. That is how we can follow and understand progress.” – specialist physician, Indiana
 - “We use it to find/identify patients to facilitate further intervention. From there, the reports are helpful to guide efforts. We can deploy resources to improve outcomes.” – social worker, Ohio
 - “Avoidable occurrences are tracked and shared annually. We also get a monthly productivity report with results. Outcomes are tracked regularly through the dashboard.” – nurse care manager, North Carolina
 - “We do the best we can. Telehealth has been very helpful to folks with mobility issues or have wounds or cannot get to the office. We have been able to get them equipment over the phone. If they need equipment to ambulate and cannot get to the office, they can talk to them via telehealth.” – primary care physician, Texas
 - “We have an Aunt Bertha (now called FindHelp) which is our community resource directory embedded in EMR. We use that all the time and any person on team can go to that.” – social worker, Ohio

Better for Health Care Team Members

Study participants also indicated that practicing in an ACO is better for members of the health care team because:

- The team approach to care enables different professionals to work together to provide optimal care to patients.
 - “We are getting more support to do what we wanted to and more resources to help patients do better.” – primary care physician, Texas
 - “We are 1000% better because we have a team and can provide more eyes on patients. More people are involved supporting that patient. – nurse practitioner, Pennsylvania
- It expands access to care by providing additional resources and support to care for patients that need it the most without overburdening physicians and advanced practice providers (PAs and NPs). For example, nurse care managers and other health care team members like care navigators, social workers, community health workers, pharmacists, chaplains, community paramedics, etc. “can take the burden off the providers; they are an extension of the MD-RN dyad.” – nurse care manager, North Carolina
 - “Given the shortage of PCPs, the care managers and navigators are able to help their patients get in to see providers when needed as the providers will work to accommodate patients from care management and navigation.” – nurse care manager, Washington
 - “Value-based care is more interdisciplinary care with integrated behavioral health, community health workers at hand, chaplains on staff, too, who are just one phone call away. This additional support allows doctors to spend more time with patients to understand what they need. In value-based care, doctors can refer to chaplains or CHWs to help meet patients’ needs. There is the delegation of roles and responsibilities, so they don’t have to do everything. It is a benefit to them.” -community health worker, Arizona
 - “There is more collaboration and support. People working to their specialties.” – social worker, Ohio
- It allows all members of the health care team to be better at their job.
 - “The providers are happier because we can offer them more time to help close gaps to improve outcomes for all. Overworked providers are providers who miss things.” – nurse practitioner, Pennsylvania
 - “The providers want to practice good medicine but the pressure to bill [under FFS] is not good medicine. I firmly believe doctors are good and want to help people, so empower them to do health care in a way that is equally beneficial to both parties.” – community health worker, Arizona
 - “We are part of positive outcomes. Every day we are closing gaps and identifying needs.” – community health workers, Arizona

Examples: Here are just a few examples from the interviews of going above and beyond:

Improved Patient Care and Family Caregiver Support

- “We had a care coordination team at a primary care office and had a couple come in for their annual Medicare visits. He had advanced dementia and she was trying to take care of him at home with no resources. They expected it [due to his family history] and had saved money for it but didn't have a plan. The care coordination team actually reached out to us and said, ‘Hey, can you guys help them, they're really struggling.’ I now have both of them on my care management services and it has just been tremendous. I mean, just caregiver [burnout] education for his wife. Like what the expectations are, how to do self-care and how to manage her stress and then get her resources for care. In the home with her husband, she had not slept in days. When I started talking to her, we set up services for her in the nighttime hours, so she could get some sleep and within a week, it was like talking to a different person. She said, ‘I didn't realize how to the end of my rope that I was—that I was just spiraling.’ It is stories like that on a routine basis that I'm not even sure the doctor's office knows how to help them. But we immediately got her some assistance with house cleaning. We got her some assistance with the nighttime caregivers. We've been working on caregiver stress with her as well as dementia education as to what to expect and his safety and when to know when she can no longer do this. I've had them for about 1.5 months now and the difference in talking with her on a regular basis is--she's just always so grateful. She's so appreciative. And you know, you can hear the smile in her voice. On the phone, she doesn't even say hello anymore--she greets me by my name.” – nurse care manager, North Carolina
- "One of our patients in his mid-70s had frequented the ER approximately 46 times the previous year. Realizing the need for intervention, our care manager began weekly check-ins, addressing medication refills and doctor visits, significantly reducing ER visits to just twice in the following year. This proactive approach not only reduced health care expenses but also ensured better care for the patient. Now, many patients prefer interacting with the care manager over directly communicating with the doctor.” – primary care physician, Kansas
- “We had a patient who, when [we] started following him, his A1C was greater than 18. He was Spanish speaking, had a daughter in NJ but wouldn't use the phone. We communicated with his daughter and ordered a home health nurse to help with him and his daughter. We followed him very closely and they were able to get A1C down by half.” – nurse care manager, Washington
- “We had a patient who had a stroke and memory loss and got involved with a primary care provider (PCP). Then [a social worker] got involved because the caregiver, who provided home care had depression. The [registered nurse] and [social worker] tag teamed with the patient and PCP. They have developed an intensive care management approach in-house for 12 weeks. We found out [the patient] was seeing ghosts, hallucinating and [we] were able to get her in with a neurologist to make sure she was able to get recommended resources and connecting her to counseling and services in the home.” – social worker, Ohio

Health Care Teams that Work Together

- “I had one gentleman last April who had an A1C of 11.6 (high). I outreached to him and found that he was a landscaper and went to McDonalds for lunch [where] he had coffee, sodas and added sugars. He had hypoglycemia and was losing weight because his blood sugar was high. He did not want to take medication and wanted to do it on his own by changing his diet. He needed [a prescription] and worked on a diet. His wife was a nurse and told him repeatedly that she was willing to make him lunch like salads. He wanted to be held accountable. We followed him for 4.5 months. The doctor set up 2-month checks for his A1C, got him down to 6.7 [during that time]. Medications and diet had great results. We do not give up and might need to give them time. We see success stories and we want to just keep doing it. It is a team effort between doctor, pharmacy and the nurse. Community Health Workers (CHW) are key for psychosocial peace, addressing language barriers and patients who are lost to care. CHW navigators' outreach to patients is instrumental because they are bilingual. It is a 3-way call or outreach to a patient first. It works on patients between 140-149 and we do over 149 with some teaching. At some point they connect to CHW.” – nurse care manager, Massachusetts
- “The patient was living in a friend's garage without a car or job and needed affordable medication. The team worked to identify cost-effective drugs, ensuring the patient's granddaughter picked up and delivered the medication, ultimately getting the patient on the necessary meds and to their appointments.” – pharmacist, Ohio

Greater Patient Engagement

- “I had a patient who was going back and forth to the emergency room for heart failure. The patient was in chronic care management but was not using it and he was not connected to the right specialty providers. I had to talk to him and put him in a heart failure clinic (even though he liked his cardiologist). Once he transferred to heart failure clinic, his emergency room visits stopped. The care manager did have a lot of work to do. There was no way I would have been able to find the time to do this without the care manager.” – primary care physician, Delaware
- “We have a bat phone, which was started to help patients prevent emergency room visits. We will start to roll out home-based visits and will send a medical assistant with [an] iPad to connect with [a] provider in the office while assessing living conditions and taking vitals. We use scribes to help with connectivity with the patients so [the providers] can look patients in the eyes. We build trust. We can afford it because value-based care allows us to do it.” – nurse practitioner, Pennsylvania

Opportunities for Improvement: Health care team members shared what they thought would improve the ACO model:

| Suggested Improvements | Supportive Quotes |
|--|--|
| <p>Stronger push toward value-based care such as ACO models to encourage broader access to the model.</p> | <p>- "There needs to be a greater push toward value-based care because we are still in limbo between fee for service and value-based care. In value-based care, you are better able to provide needed services for patients. For example, remote patient monitoring isn't done in the fee for service. Value-based care allows earlier intervention and makes sure patients stay healthy." – specialist physician, Indiana</p> <p>- "I think other populations besides those on Medicare or MA should be able to get the services provided by the ACO model." – nurse care manager, North Carolina</p> |
| <p>Move away from fee for service, aligning incentives and allowing more upfront funding and flexibility, with less rigid rules and bureaucratic hurdles, including inconsistency in rules across programs and payers.</p> | <p>- "Providing care under the ACO model is better, results in better outcomes, is more focused on the whole patient and whole family care. The downsides are that you see the limitations of working on a fee for service chassis as well as the variations in how different payers approach value-base care, which can be very frustrating." – primary care physician, Delaware</p> <p>- "Those in FFS are too quick to order MRI and other expensive tests. There is a lot of money wasted in FFS." – nurse care manager, Massachusetts</p> |
| <p>Improve payment for primary care.</p> | <p>- "The payment of primary care physicians is flawed, especially for doing good work." – primary care physician, Kansas</p> <p>- "We are limited by the number of PCPs, mid-levels and MDs. 6000 attributed to each so it is too hard to see these people adequately, especially those with high socio-economic needs. We need to pay them as if primary care is important." – community health worker, Arizona</p> |
| <p>Supporting educational efforts highlighting the benefits of value-based care such as ACO models to patients and providers.</p> | <p>"I think buy-in is really what needs to be step one and people to get more information out about how the ACOs are beneficial and to get providers to understand, from all levels in the healthcare spectrum, what the benefits are and how it has already been impactful to the people that have been involved." – nurse care manager, North Carolina</p> |
| <p>Ensure models like ACOs promote continued provider participation and reward performance improvement and high quality.</p> | <p>"There should be better oversight of payers who keep raising the bar and reducing compensation." – primary care physician, Kansas</p> |

| Suggested Improvements | Supportive Quotes |
|---|--|
| Improve data sharing. | <ul style="list-style-type: none"> - "Not all the payers provide the information, which is unfortunate because HIEs are costly." – primary care physician, Delaware - "Admission, discharge, transfer (ADT) feeds are not as good as I'd like because we only get 1/3 of discharges at present because not all facilities provide that information." – primary care physician, Florida - "There continue to be barriers and challenges communicating with providers outside the network." – primary care physician, Texas - "Groups are not on the same medical record. It would be better if they were and then the patient feels that everyone is on the same team. There would be less guessing and an improvement in communication and quality." – primary care physician, Kansas - "Without good data, it would be difficult to identify, follow and track outcomes." – pharmacist, Ohio - "The independent providers who are not on the same EHR are harder populations to manage because of lack of information." – social worker, Ohio |
| Address workforce shortages in primary care, mental health and social work. | <ul style="list-style-type: none"> - "You're going to have to grow the workforce that's doing the work to provide the care." – nurse care manager, North Carolina - "There are not enough primary care physicians." – community health worker, Arizona - "We need to feed primary care to reduce the need for specialty sick care." – nurse practitioner, Pennsylvania - "Mental health is one of our biggest challenges and we are providing more mental health services, but there aren't enough mental health providers to refer patients for mental health problems." – primary care physician, Delaware - "Increasing the number of social workers, as their growth positively impacts more patients." – social worker, Ohio |
| Ensure access to advance information about patient out-of-pocket expenses for patients and providers. | <p>"Access to information about patient out-of-pocket expenses needs to be done nationally! It shouldn't be that difficult." – primary care physician, Florida</p> |
| Improve providers ability to address non-medical drivers of health. | <p>"I wish there was a way to better reduce transportation barriers and simplify how transportation services are provided." – community health worker, Arizona</p> |

Providing care through an ACO compared to Traditional Fee for Service

Health care team members compared care provided under an ACO model to traditional fee for service, and below are examples of what health care team members had to say:

- Better outcomes
 - “The additional services provided by the ACO has resulted in very high satisfaction rates. There is a big focus on the community we serve, [putting] patients first and making sure they get what they need. This also has had a positive impact on health outcomes because the added supports also allow them to identify and address health-related needs. They can monitor outcomes through a dashboard that marries claims and EHR data. That is how we can follow and understand progress.” –specialist physician, Indiana
 - “ACOs are more proactive rather than reactive. The data provided by ACOs allows the health care team to address gaps in care more effectively.” –primary care physician, Kansas
 - “The ACO model has grown so much in a short amount of time and patients receive better long-term care. It puts responsibility on all members of the team to pay attention and care for the patient to ensure that, long term, they continue to receive the best care. It is not a one and done.” – pharmacist, Ohio
- More services and support provided by a team of health care professionals
 - “In fee for service, there are no wrap around services and supports. When service ends, their care ends. But with the ACO, the service continues to ensure the patient has what they need to stay healthy and get the level of care that they need, so [the care] just does not drop off after [leaving] the office. Under fee for service, we do not have time to do the necessary patient education about meds... [T]he patients came in, we provided services and they would leave. The ACO provides wrap-around services. The nurse, social worker and pharmacist have eyes on them at all points over their health care journey. There are more eyes on patients to ensure they have a resource to help navigate.” – pharmacist, Ohio
 - “Unlike fee for service, patients in an ACO get better care because there is an interdisciplinary team working together to help ensure patients get what they need.” – community health worker, Arizona
 - “We try to get them the care they need as quickly as possible, right care at the right time.” – social worker, Massachusetts
- More holistic (complete, well-rounded, thorough) approach to care
 - “I would say it's really holistic now. Under fee for service, the focus was on what the patient was in the hospital or being treated for: ‘Here's what the treatment is, if you have another problem, follow up with somebody else.’ But under the ACO: it is more holistic, including mental health as well as other comorbidities, socials needs, all of those things are being looked at the same time.” – nurse care manager, Washington

- “In my practice we have one MD and NP, 6 medical assistants and front office staff and office manager all part of team. The ACO has made it better. We have been able to explain why we are doing things. We coordinate better and it makes us work together as a team to coordinate what needs to be done. It helps everyone understand.” – primary care physician, Texas
- “The care provided by the [ACO] model is superior; quality of care is significantly higher because the model takes a holistic approach, considering the person as a whole rather than as separate parts.” – social worker, Ohio
- Improved health equity:
 - “One way the ACO tries to address inequities is ensuring that they have employees who are from the communities they serve. For example, in Texas and Arizona, all the community health workers (CHWs) are fluent in Spanish and English and most of the CHWs are Hispanic and thus are also familiar with the culture.” – community health worker, Arizona
 - “I am on the diversity committee. It is in the hiring practices of leadership. Seeing someone like them helps patients. There also are some reports stratified on race and ethnicity. There is a big push on congestive heart failure. We categorize high-risk zip codes and then race and ethnicity. The community healthcare workers lead interventions.” – social worker, Ohio
 - “As a whole our organization has put a focus on the disparities and has done studies. We are really focusing on disparities in heart failure and diabetes and looking at the reason for the disparities with a focus on the social determinants of health and providing programs to help address this.” – social worker, Massachusetts
- Better coordination of care:
 - “In fee for service, you are just seeing patients. Everyone was on their own, no one was overseeing patients’ health. We were not all on the same page and were unaware of preventive care. We were practicing in patient churn. More communication was needed. Value-based care is behind the scenes so you can make the most of the time with the patients. It has helped me stay in private practice. When practicing in fee for service, I felt very restrained because of the limitations of the fee for service system. In value-based care, I can practice the way I want to practice.” – primary care physician, Delaware
- Focus on preventive care:
 - “Under fee for service, annual wellness visits were being done inconsistently and now those visits are encouraged under the ACO to ensure preventive services are completed. Patients are going to the emergency department less frequently than before because there are good mechanisms in place to get patients in and taken care of earlier. We were so passive in medicine for many years waiting for [the patient] to come in, but now we go more upstream and contact patients and they think it is important. Hope was never a good strategy.” – primary care physician, Florida

- “Before people didn’t focus on preventative care or keeping folks healthy, it was just treating the problem at hand.” – nurse care manager, North Carolina
- “Fee for service doesn’t prioritize preventive care or encourage active participation in your own health care.” – community health worker, Arizona
- Better for patients and providers
 - “Fee for service is not sustainable and it is exhausting. It is not fair to patients, because there is an exhausted overworked provider.” – nurse practitioner, Pennsylvania
 - “[Under the ACO], we are getting more support to do what we wanted to and more resources to help patients do better.” – primary care physician, Texas
- Less waste
 - “There is [a lot] of wasted, unnecessary procedures and testing and a lot of money wasted in fee for service.” – nurse care manager, Massachusetts
 - “Lots of patients were in hospitals that didn’t need to be there. It’s part of the reason I took the job. People come to hospital because of lack of resources.” – nurse care manager, North Carolina

Discussion

The purpose of this study was two-fold. First, given the small number of patient and consumer advocacy organizations actively participating in value-based care discussions, we wanted to be able to engage more patient and consumer advocacy groups in these discussions to ensure that patient and consumer voices are adequately represented on issues addressing health care delivery and payment reform. Second, to enhance the engagement of these groups and others, including policy makers, not familiar with health care delivery and payment reform, we want to be able to discuss it in a way that is relatable to individuals and organizations not steeped in the highly technical jargon frequently used in these discussions.

To achieve these goals, this research was designed to capture the experience of patients, their family caregivers and members of the health care team experience—those on the frontlines receiving and delivering care—in advanced alternative payment models and use their experience to describe the attributes of these models from their perspectives.

The semi-structured key informant interviews covered a range of topics relevant to enhancing the patient experience and as noted previously, the questions were informed by a review of academic and gray literature on patient experience and person- or patient-centered care, an expert panel with representatives from 15 consumer, patient and multi-stakeholder organizations, as well as a number of other organizations with interest or expertise in value-based care. The interview guides can be found in Exhibits A and B.

The themes that emerged from the interviews help provide a better way of communicating the benefits of the ACO and similar models without resorting to the

technical jargon and provider-centric language frequently used, i.e., talking about how providers get paid and the incentives behind the payment change. When talking to patient and consumer advocacy groups, we need to focus on what it means from the patient's perspective and from the perspective of those providing the care. For example, being cared for through an ACO means that medically complex patients receive better care, outcomes and support because they have a dedicated primary care relationship that is essential to long-term continuity and coordination of care and services, a team of health professionals that work together to ensure all the patients' physical, mental and social health needs are understood and met and better communication and engagement opportunities that improve access to health care team members when needed, all of which lead to more trusting relationships, better health outcomes and more satisfied patients and families. The care provided through an ACO allows health care professionals to work together to provide better and more holistic care and enhanced access and support for their patients, leading to improved health outcomes and improved professional and patient satisfaction.

Importantly, all ACOs are not uniform, some are more sophisticated than others and there is always room for improvement. Most ACOs also have not had the benefit of truly engaging patients, consumers and communities in care delivery redesign efforts. To be person- or patient-centered, engaging patients, consumers and their advocates at the community level has the potential to further enhance the efficacy of the ACO and similar models, which is a major reason for undertaking this research.

Despite the advantages of receiving and providing care through an ACO, engagement among patient and consumer advocacy organizations and their constituents is lacking. More organizations need to understand the significant benefits and what can be accomplished for their constituents so they will engage in policy discussions to ensure that ACOs and similar models continue to meet the needs of their constituencies to improve the care, services and support provided to help patients attain their health goals. A collective and elevated patient and consumer voice is needed to safeguard the attributes that promote health and guard against practices that thwart optimal health. As value-based care continues to gain traction through increased adoption across all payers, the time to engage, educate and advocate is now.



Exhibit A—Literature Review Bibliography

Carbajal E. 'A total disruptor to how we do business': Cleveland Clinics new patient experience metric, Becker's Hospital Review. September 2, 2022.

<https://www.beckershospitalreview.com/patient-experience/a-total-disruptor-to-how-we-do-business-cleveland-clinic-s-new-patient-experience-metric.html>

Chernew ME, Mechanic RE, Landon BE, Safran DG. Private-payer innovation in Massachusetts: the 'alternative quality contract'. Health Aff (Millwood). 2011;30(1):51-61. doi:10.1377/hlthaff.2010.0980

Chi W et al. The Whole Health Index: A Practical, Valid, and Reliable Tool to Measure Whole-Person Health and Manage Population Health. NEJM Catalyst. May 30, 2023. DOI: 10.1056/CAT.23.0015

Cleary PD, Edgman-Levitan S. Health care quality. Incorporating consumer perspectives. JAMA. 1997;278(19):1608-1612.

[Cohen M et al. Could Person-Centered Care Be The Secret To Achieving The Triple Aim? Health Affairs. July 13, 2022.](#)

Donabedian A. The seven pillars of quality. Arch Pathol Lab Med. 1990;114(11):1115-1118.

Epperly T, Bechtel C, Sweeney R, et al. The Shared Principles of Primary Care: A Multistakeholder Initiative to Find a Common Voice. Fam Med. 2019;51(2):179-184. doi:10.22454/FamMed.2019.925587

Farhana N, Peckham A, Marani H, Roerig M, Marchildon G. The Social Construction of Dementia: Implications for Healthcare Experiences of Caregivers and People Living with Dementia. J Patient Exp. 2023;10:23743735231211066. Published 2023 Nov 5. doi:10.1177/23743735231211066

[Grossman R. Cotiviti White Paper. Developing trust with Medicare Advantage members through better engagement. 2022.](#)

Huang K, Konig M, Psocka MA, Wadhwa RK, Joynt Maddox KE. Cardiovascular Patient Perspectives on Value in the Healthcare Experience. Circ Cardiovasc Qual Outcomes. 2020;13(6):e006617. doi:10.1161/CIRCOUTCOMES.120.006617; and [American Heart Association. Patients Want 5 Things. Value in Healthcare Initiative; 2018.](#)

Manary M, Boulding W, Staelin R, Glickman S. The Patient Experience and Health Outcomes. NEJM. Jan 2013. DOI: 10.1056/NEJMp1211775.

McWilliams JM, Landon BE, Chernew ME, Zaslavsky AM. Changes in patients' experiences in Medicare Accountable Care Organizations. *N Engl J Med*. 2014;371(18):1715-1724. doi:10.1056/NEJMs1406552

Shaller D. Patient-Centered Care: What Does it Take? Commonwealth Fund. Oct 2007.

Travares J, Cohen M, Hwang A, Hawes F. Person-Centered Care: Why Taking Individuals' Care Preferences into Account Matters. Center for Consumer Engagement in Health Innovation, Community Catalyst; The SCAN Foundations, and Leading Age. Mar 2022.

Agency for Healthcare Research and Quality. What Is Patient Experience? Content last reviewed September 2023. Agency for Healthcare Research and Quality, Rockville, MD. <https://www.ahrq.gov/cahps/about-cahps/patient-experience/index.html>.

[American Association of Colleges of Nursing, Person-Centered Care.](#)

Becker's Healthcare. How leading health systems leverage digital tools to improve price transparency, patient experience. Becker's Healthcare // RevSpring. July 2022.

CAHPS Clinician & Group Survey 4.10. Oct. 20, 2010.

CMMI Communications Snapshot: Accountable for Health. December 13, 2023. CMS.

[CMS definition of person-centered care.](#)

[Coalition to Transform Advanced Care \(CTAC\) Core Principles for Models with Serious Illness Population.](#)

Health Care Transformation Task Force Resources: <https://hcttf.org/resources-perspectives/#patient-centered-care>.

[HealthLeadsUSA.org. 4 C's of Patient Centered Care.](#)

Humana. Value-Based Care Report 2023.

Institute of Medicine (US) Committee on Quality of Health Care in America. *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington (DC): National Academies Press (US); 2001.

National Health Council. The National Health Council Rubric to Capture the Patient Voice: A Guide to Incorporating the Patient Voice into the Health Ecosystem. June 2019. Washington, DC. Available from: <https://www.nationalhealthcouncil.org/Patient-Engagement-Rubric>.

[National Health Council. Domains of Patient Centeredness in Value Assessment.](#)

National Health Council. The Patient Voice in Value: The National Health Council Patient-Centered Value Model Rubric. May 2016.

The CMS Innovation Center’s Beneficiary Engagement Listening Session Slides. Incorporating Beneficiary Perspectives into Model Testing, Implementation and Evaluation. Feb 2022.

The CMS Innovation Center’s Approach to Person-Centered Care. Engaging with Beneficiaries, Measuring What Matters. Sept 2022.

Vital Signs Report Brief. Cost Metrics for Health and Health Care Progress. Institute of Medicine of the National Academies. April 2015.

[NEJM Catalyst. Innovation in Care Delivery. The Whole Health Index: A Practical, Valid, and Reliable Tool to Measure Whole-Person Health and Manage Population Health. Oct 2023. DOI: 10.156/CAT.23.0025.](#)

NEJM Catalyst. What is Patient-Centered Care? Jan 2017.
<https://catalyst.nejm.org/doi/full/10.1056/CAT.17.0559>

[Smart Communications. 2023 Benchmark Report: The State of Healthcare Customer Experience; 2023.](#)

National Association of Accountable Care Organizations. [NAACOS ACOs & Patients: Care Focused on Individuals.](#)

National Association of Accountable Care Organizations. [NAACOS Patient Engagement Survey Report. 2023.](#)

National Association of Accountable Care Organizations. What It Means to Patients: Medicare Shared Savings Program.

NAACOS. Recruiting & Engaging Patient Representatives: Foundations & Best Practices for ACOs.

[National Academy of Medicine. Vital Signs. Core Metrics for Health and Health Care Progress. Reducing Burden, Sharpening Focus, Improving Performance. 2015.](#)

PCORI. Engagement in Research: Foundational Expectations for Partnerships. February 2024.

PCORI. Stakeholder Views on Components of “Patient-Centered Value” in Health and Health Care. May 2023.

[RevSpring. 10 Consumer Strategies Patients Expect Now.](#) RevSpring. 2020.

The University of Utah. The Status of Value in U.S. Healthcare. Available at:
[https://uofuhealth.utah.edu/value.](https://uofuhealth.utah.edu/value)

Value in the States Principles. “Patient engagement | health care leads to better health outcomes, better care, and lower costs....” Multiple Patient Advocacy Organizations

[ZS's Future of Health Survey Report | Future of Healthcare.](#) 2023.



Exhibit B—Key Informant Interview Guide for Patients and Caregivers

1. Introduction: Hello, my name is Melanie Phelps, and I am the principal investigator. I work at the American Heart Association as Senior Advocacy Advisor, Health System Transformation. I am also a family caregiver who has had good and bad experiences with the health care system, and I am interested in learning more about your experience and interactions with the health-related care and services you receive from your health care providers/team practicing in this care delivery and payment model. I am looking forward to hearing your insights and thoughts about your health care experiences.

This research is being conducted by the American Heart Association and is funded by a grant from Arnold Ventures, a philanthropy dedicated to improving the lives of everyone in the United States through evidence-based policy solutions that maximize opportunity and minimize injustice.

A \$100 stipend is available to compensate you for completing the full interview. As you know, the interview will take about 60 minutes. I know you are busy, and I appreciate your time, so let us get started.

2. Informed Consent: [Note: If informed consent has been reviewed and obtained, ask: When we last talked, we reviewed the informed consent form, do you have any questions? Pause to let them answer. Then ask: Do you still give your consent to be interviewed and have the interview recorded. << *The information below is here in case they would like to review it again.* >>]

This research is being conducted pursuant to a grant by Arnold Ventures to the American Heart Association to learn about patient, family caregiver/support person, and health care team member experiences with health care organizations committed to and responsible for improving experience of care, services, and health outcomes (value-based arrangements). The principal investigator (PI) is Melanie Phelps, DrPH, JD, with the American Heart Association. The research assistant (RA) is Aalaya Gurram, with the American Heart Association. Together the PI and RA make up the “Research Team.”

The purpose of this research is to understand and describe the benefits of person-centered, quality-focused (value-based) care by hearing the perspectives and experiences of patients, family caregivers/support persons and health care team

members in value-based arrangements. The learnings from this research will be used to advocate for improving health care experience, services and outcomes for everyone. To be eligible to participate, study participants must be affiliated with a value-based arrangement and be or care for a patient(s) who are medically complex.

If you agree to take part in this research, you will be asked to provide some information ahead of time either by phone or email, and then participate in a 60-minute key informant interview. We expect up to 30 people will take part in this research.

Participating in this research is completely voluntary. You can choose not to be interviewed. You also can say yes now and change your mind at any time. You also will be asked if you agree to the interview being recorded, which aids the research process. Recording of the interview, however, is optional.

Upon completion of the 60-minute interview, a \$100 stipend (gift card) will be sent to you via mail if you choose to claim it.

The possible risks to you of taking part in this research are:

- Although highly unlikely, a breach of confidentiality could occur.

The possible benefits to you for taking part in this research are:

- Helping to generate a better understanding of what the experience of care is like in value-based arrangements.
- Informing advocacy and policy making to improve health care and services for all people.
- Helping to accelerate adoption of value-based arrangements more broadly.

The interview will be recorded over Microsoft Teams or Zoom and transcribed to aid in analysis. All reasonable steps will be taken to protect the identity of study participants. Information obtained pursuant to this research including audio recordings, transcripts, and notes will be accessible only to the Research Team, kept confidential, and stored securely on a secure site at the American Heart Association that will be password protected and accessible only to the Research Team. A letter and number coding system will be used to protect the identity of study participants. A list that matches the coding system to the participants will be kept in a separate and secure location that is accessible only to the Research Team. The code list and other information obtained as part of this research will be stored securely for the

duration of the research project (no later than December 31, 2024), after which time the information will be destroyed.

In any report, publication or communication of research findings, information obtained pursuant to this research will not be attributable to the study participant beyond the Research Team. Code names, however, may be assigned and used.

This project has been reviewed and approved by the Heartland Institutional Review Board.

Questions concerning your rights as a participant in this research may be addressed to the Executive Director at Heartland IRB. Office: (866) 618-HIRB [4472]; Fax: (866) 414-0517; or by emailing director@heartlandirb.org.

If you have any questions about this research, you may contact the Principal Investigator: Melanie Phelps, Senior Advocacy Advisor, Health System Transformation, at the American Heart Association at melanie.phelps@heart.org; or at 919-306-5123.

Do you give your informed consent to proceed with this interview? Y or N

If yes, please state your Name _____ Date: _____

Do you agree to allow the interview to be recorded? Y or N

If yes, the interview will be recorded; if no, then the interview will proceed and only notes will be taken.

3. Background for Patients: Your doctors and other health care providers who help take care of you—your “health care team”—participate in a program that is designed to improve the health care and treatment you receive, and this research seeks to understand whether those goals are being met and result in a better care experience and improved health outcomes.

4. Questions for Patients:

| Questions | Interview Notes |
|---|-----------------|
| Introductory Statement: To get a better understanding of your care experience we'll begin by asking some questions about your health conditions and what your goals are for the health-related care and services you receive, and then we'll talk about your care experience. I'll ask some open-ended and some specific questions. Before we dig in, do you have any questions for me? | |

| Patient Background Information Including Goals of Care | |
|--|--|
| <p>1. Can you tell me a bit about yourself? Prompts (will depend on participant): Who is important in your life? Where are you from originally? What was your occupation? What do you like to do for fun?</p> | |
| <p>2. Does anything get in the way of doing the things you like to do? Prompts: Illness, pain, physical ability, accessibility of services or activities</p> | |
| <p>3. What are the main health issues or top medical conditions you are dealing with, and how long have you been dealing with these health issues? Prompts: Any others?</p> | |
| <p>4. Can you briefly describe your overall experience in receiving health care especially related to your current health condition(s)? Prompts: Take me through the steps—from scheduling appointments to the visits with different health care professionals, the follow-up care, etc.? Think about it as if you were going to map it out for me.</p> | |
| Care Team Interactions and Care Coordination/Management | |
| <p>5. Is there a person who usually helps you make health-related appointments or who you call when you need something? If yes: Who is that person? Prompts: Is there one or more people who help arrange appointments or services?</p> | |
| <p>6. Who do you see or talk to most often for your health and other care? Prompts: Who is the first person you try to see with a health-related issue?</p> | |
| <p>7. How long and/or how often do you interact with this person, and how satisfied are you with your interactions?</p> | |
| <p>8. Do you see any other doctors or providers, like nurses, social workers, pharmacists, care managers or navigator, community health workers, etc.?</p> | |

| | |
|--|--|
| <p>9. How long and/or how often do you interact with this person, and how satisfied are you with your interactions?</p> | |
| <p>10. When choosing a specialist, how do you decide who to go to? Prompts: Existing relationship, recommendation from your health care team, family, friends, etc.</p> | |
| <p>11. Do you feel your doctors and health care team members talk to each other about your care? Prompts: Do you think they work together to manage your care; are they knowledgeable about what the others have recommended?</p> | |
| <p>12. Beside your doctors and other health care team members, where do you get information about your conditions and/or treatments and which sources do you believe or rely on the most? Prompts: Other doctors or health care team members, internet, social media, family or friend, TV etc.</p> | |
| <p>13. Are you asked about or do you see anyone for mental, emotional, or spiritual health needs, and are you satisfied with the attention given to these needs? Prompts: Psychiatrists, psychologists, therapists, counselors, social workers?</p> | |
| <p>14a. Are you asked about whether you need help with non-medical issues such as food, housing, transportation assistance? (If so, have you been referred to any outside organization to help meet those needs? Can you please give some examples.)</p> | |
| <p>14b. If referred to a CBO, ask: Did they help meet your needs (CBOs), and how satisfied are you with the services?</p> | |
| <p>15. Do your health care providers seek to understand what is important to you when recommending treatment and medical care, and do they ask about your goals for your</p> | |

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| <p>overall health? How are these goals being addressed by your health care team? Prompts: Do your health care providers ask about what you want to get from your medical care, such as do you want your condition controlled, pain control, able to do certain activities, etc.?</p> | |
| Access & Affordability Issues | |
| <p>16. Are you able to get in to see or to talk to your health care providers when you need to (drill down as appropriate), and can you share specifics about your experience getting in touch with your providers to meet your needs? Prompts: How difficult or easy is it to make an appointment or talk to someone? Can you get in to see them in a reasonable amount of time?</p> | |
| <p>17. Do you feel that each health care provider spends enough time with you? (drill down as appropriate) Prompts: Do you ever feel rushed during appointments/visits? Or do you feel that the provider is willing to spend as much time with you as needed? Are some better than others?</p> | |
| <p>18. Have you ever felt that you were treated differently from other patients for any reason? Prompts: Health status or condition, disability, age, culture or religion, language or accent, race or ethnicity, sex, income level, sexual orientation, gender identity, income?</p> | |
| <p>19. Either recently or in the past, have you ever been denied care for any reason? If so, could you give specifics on when and why you think that occurred? Prompts: Insurance, health status or ability, etc.</p> | |
| <p>20. Are you seen in a place or manner that is convenient and/or easy to access? Prompts: Do you have to go to a physical location? Does anyone come to your home or community? What about virtual or telehealth visits?</p> | |

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| <p>21. What are the ways you can communicate with your health care providers during off hours, and are these methods timely and effective? Prompts: Special number or person to call, patient portal, etc..; how quickly do you get a response?</p> | |
| <p>22. How well do your doctors and other health care providers share your test results and other important information? Prompts: How good are they getting you that information in a timely manner?</p> | |
| <p>23. Are you given information about the cost of medications and other medical treatments or procedures when discussing treatment options with your health care providers or team?</p> | |
| <p>24a. How much of a problem have the costs that you would need to pay for medications and other medical treatments or procedures been, and do you talk about this with your providers? And if so, please provide more detail.</p> | |
| <p>24b. If costs have been a barrier, ask: "Do your health care providers work with you to find assistance or alternative treatments that are more affordable?"</p> | |
| <p>Person-Centeredness/Communication</p> | |
| <p>25. How respectful and responsive is the care you receive? Prompts: How are your personal/individual needs and preferences addressed when treatment recommendations are made?</p> | |
| <p>26. Do you feel heard and understood by your health care providers and/or health care team, and that your best interests are put first when making recommendations about your care? Prompts: Are you asked what your wants and needs are?</p> | |
| <p>27. Do you feel your health care providers and team see you as a person, and not just</p> | |

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| someone with a medical problem, and do they understand what is important in our life? Prompts: Do you feel you treated as a person outside your medical issues, or more as a symptom or disease? | |
| 28. How well do your health care providers explain things to you? Prompts: Do you usually understand what they are saying? | |
| 29. Are there health care providers or team members that you trust more than others? Why? Prompts: Who do you trust vs who you do not trust and why? | |
| 30. How comfortable are you challenging, questioning, or pushing back on recommendations by your health care providers when something does not feel right? Prompts: If you have an issue or concern with what is being recommended, do you feel comfortable asking questions or seeking another opinion? | |
| Concluding Questions | |
| 31. What do you like best about the care you get? | |
| 32. How could it be even better? | |
| 33. Do you have any other thoughts on anything we discussed that you would like to share? | |

5. Wrap-up

Thank you for your time and sharing your experiences and views. Please let me know if you would like to receive the \$100 gift card and if so, I just need to make sure I have the correct address.

- [Confirm proper name]
- [Confirm proper mailing address]

Would you be willing to do a written or video testimonial about your experience?
Y or N

Thanks, again, if you have any questions or concerns, please contact Melanie Phelps.

Contact Information

Melanie G Phelps, principal investigator: melanie.phelps@heart.org; 919-306-5123



Exhibit C—Key Informant Interview Guide for Health Care Team Members

1. Introduction: Hello, my name is Melanie Phelps, and I am the principal investigator. I work at the American Heart Association as Senior Advocacy Advisor, Health System Transformation. I am also a family caregiver who has had good and bad experiences with the health care system, and I am interested in learning more about your experience and interactions with the health-related care and services the person you support in this care delivery and payment model. I am looking forward to hearing your insights and thoughts about your health care experiences.

This research is being conducted by the American Heart Association and is funded by a grant from Arnold Ventures, a philanthropy dedicated to improving the lives of everyone in the United States through evidence-based policy solutions that maximize opportunity and minimize injustice.

A \$100 stipend is available to compensate you for completing the full interview. As you know, the interview will take about 60 minutes. I know you are busy, and I appreciate your time, so let us get started.

2. Informed Consent: Note: If informed consent has been reviewed and obtained, ask: When we last talked, we reviewed the informed consent form, do you have any questions? Pause to let them answer. Then ask: Do you still give your consent to be interviewed and have the interview recorded. << *The information below is here in case they would like to review it again.* >>

This research is being conducted pursuant to a grant by Arnold Ventures to the American Heart Association to learn about patient, family caregiver/support person, and health care team member experiences with health care organizations committed to and responsible for improving experience of care, services, and health outcomes (value-based arrangements). The principal investigator (PI) is Melanie Phelps, DrPH, JD, with the American Heart Association. The research assistant (RA) is Aalaya Gurram, with the American Heart Association. Together the PI and RA make up the “Research Team.”

The purpose of this research is to understand and describe the benefits of person-centered, quality-focused (value-based) care by hearing the perspectives and experiences of patients, family caregivers/support persons, and health care team members in value-based arrangements. The learnings from this research will be

used to advocate for improving health care experience, services, and outcomes for everyone. To be eligible to participate, study participants must be affiliated with a value-based arrangement and be or care for a patient(s) who are medically complex.

If you agree to take part in this research, you will be asked to provide some information ahead of time either by phone or email, and then participate in a 60-minute key informant interview. We expect up to 30 people will take part in this research.

Participating in this research is completely voluntary. You can choose not to be interviewed. You also can say yes now and change your mind at any time. You also will be asked if you agree to the interview being recorded, which aids the research process. Recording of the interview, however, is optional.

Upon completion of the 60-minute interview, a \$100 stipend (gift card) will be sent to you via mail if you choose to claim it.

The possible risks to you of taking part in this research are:

- Although highly unlikely, a breach of confidentiality could occur.

The possible benefits to you for taking part in this research are:

- Helping to generate a better understanding of what the experience of care is like in value-based arrangements.
- Informing advocacy and policy making to improve health care and services for all people.
- Helping to accelerate adoption of value-based arrangements more broadly.

The interview will be recorded over Microsoft Teams or Zoom and transcribed to aid in analysis. All reasonable steps will be taken to protect the identity of study participants. Information obtained pursuant to this research including audio recordings, transcripts, and notes will be accessible only to the Research Team, kept confidential, and stored securely on a secure site at the American Heart Association that will be password protected and accessible only to the Research Team. A letter and number coding system will be used to protect the identity of study participants. A list that matches the coding system to the participants will be kept in a separate and secure location that is accessible only to the Research Team. The code list and other information obtained as part of this research will be stored securely for the

duration of the research project (no later than December 31, 2024), after which time the information will be destroyed.

In any report, publication or communication of research findings, information obtained pursuant to this research will not be attributable to the study participant beyond the Research Team. Code names, however, may be assigned and used.

This project has been reviewed and approved by the Heartland Institutional Review Board.

Questions concerning your rights as a participant in this research may be addressed to the Executive Director at Heartland IRB. Office: (866) 618-HIRB [4472]; Fax: (866) 414-0517; or by emailing director@heartlandirb.org.

If you have any questions about this research, you may contact the Principal Investigator Melanie Phelps, Senior Advocacy Advisor, Health System Transformation, at the American Heart Association at melanie.phelps@heart.org; or at 919-306-5123.

Do you give your informed consent to proceed with this interview? Y or N

If yes, please state your Name _____ Date: _____

Do you agree to allow the interview to be recorded? Y or N

If yes, the interview will be recorded; if no, then the interview will proceed and only notes will be taken.

3. Background for Health Care Team Members: As a member of the health care team of [name of organization], which participates in the [model information], this research seeks to learn about your experience with and perspectives of practicing in the AAPM model.

4. Questions for Health Care Team Members

| Question | Interview Notes |
|----------|---|
| | Introductory Statement: To get a better understanding of your experience taking care of patients in a value-based care model, I will ask some background questions about you, and then get your thoughts and opinions on key aspects of providing health care and services under this model |

| Background Questions | |
|--|--|
| 1. What is/are your profession/discipline/credentials etc.? | |
| 2. How long have you been practicing? | |
| 3. How long have you been practicing in this model? | |
| 4. How familiar are you with the [value-based arrangement] your organization is in? Note: Can insert more information prior to interview. | |
| 5. Do you know how long your organization has been in this or other value-based care arrangements? | |
| 6. How would you describe your patient responsibilities? | |
| 7. How are patients assigned (empaneled) to you or your team? | |
| 8. Tell me about the changes that have taken place in how health care and services are provided under the model compared to fee-for-service? | |
| Health Care Team Communication, Coordination, and Collaboration | |
| 9. How has the transition to the [model] affected communication and coordination among different health care providers within the health care team? - With other providers outside your organization? | |
| 10. How is patient care coordinated? Prompts: How patients are helped through the processes of referrals inside and outside of the organization, follow-up appointment, etc. | |
| 11a. Who on the health care team is responsible for care coordination? | |
| 11b. How do you evaluate the effectiveness of care coordination or navigation services? | |

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| <p>11c. Are there any patient groups or populations that pose unique challenges to care coordination? - How are they handled?</p> | |
| <p>12a. How are transitions of care managed? Note: Where applicable, ask about pediatric to adult care transitions.</p> | |
| <p>12b. Who on the health care team is responsible for transitions of care management?</p> | |
| <p>12c. How do you evaluate the effectiveness of care transition management services?</p> | |
| <p>13. What patient populations pose specific challenges to transitions of care management? - How are they handled?</p> | |
| <p>14. Can you share examples of successful interdisciplinary collaboration within the health care team under this model? - How has it contributed to improved patient outcomes?</p> | |
| Equity | |
| <p>15. How do you, or how are you able to, address health disparities and promote equity in health care delivery within your health care team? <i>(Alt: How do you ensure that historically marginalized populations (racial & ethnic minorities; those with disabilities; those in rural areas; and those with low SES))</i> CDC definition of health equity: Health equity is the state in which everyone has a fair and just opportunity to reach their highest level of health. It requires addressing historical and contemporary injustices, overcoming economic, social, and other obstacles to health and health care, and eliminating preventable health disparities.</p> | |

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| <p>16. How does your organization ensure health equity across all populations assigned to the ACO? <i>(Alt—how does your organization check that all patients assigned to the ACO receive the equitable treatment.)</i></p> | |
| <p>17. What are ways that your organization determines and addresses existing disparities in access, experience, or outcomes for the patients you serve?</p> | |
| <p>18. How does your organization track outcomes data to monitor equitable treatment and outcomes across the populations you serve?</p> | |
| <p>19. Are there certain groups or populations of patients that your organization services that face special challenges? - How does your organization address these challenges?</p> | |
| Access and Affordability | |
| <p>20. How does your organization ensure patients have timely access to needed physical and mental health care? Prompts: Do you have a referral process that includes closing the referral loop?</p> | |
| <p>21. How does your organization ensure patients get timely access to needed social support? Prompts: Do you have a referral process that includes closing the referral loop?</p> | |
| <p>22. Are you able to provide information to patients on their out-of-pocket costs for different treatment options?</p> | |
| <p>23. How does your organization help patients who cannot afford it get and pay for the services and support they need?</p> | |
| Outcomes | |
| <p>24. Have you noticed any changes in patient satisfaction or engagement as a result of the transition to this model?</p> | |

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| - If so, how is it being measured and addressed within your team? | |
| 25. Do you feel the care provided under this model results in improved health outcomes? Please explain. | |
| 26. How are improvement in health outcomes/better health evaluated by the organization? | |
| Patient Engagement | |
| 27. Do patients have a person who is their regular or primary source of care, like a medical or health home? Prompts: Is there a primary care or other doctor or advanced practice provider who oversees patient care? Do the patients have medical or health home? | |
| 28. What steps are involved in developing an individual care plan? | |
| 29. What steps do you and your colleagues take to build trust and rapport with the patients? | |
| 30. How do you ensure that care is respectful of and responsive to a patient's needs, circumstances, and values? | |
| 31. How and how often are the patients' physical issues or needs assessed? | |
| 32. How and how often do you ensure patients' mental and emotional needs are assessed and met? | |
| 33. How and how often do you ensure that patients' social needs are assessed and met? Prompts: Food/nutrition, housing, transportation insecurity, etc. | |
| 34. How does your organization identify and make needed accommodations for different populations? Prompts: For people with disabilities or physical impairments, for those with intellectual disabilities or impairments, financial hardship, high social needs, victims of domestic violence, etc. | |

| Practice, Skills, and Culture (note—if time is running out, skip to last section) | |
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| 35. From your perspective, how has the shift to the [model] influenced the emphasis on preventive care and patient education? | |
| 36. In what ways has the [model] incentivized or motivated the health care team to focus on providing more quality-focused, person-centered, whole person care, and how does this differ from fee for service? | |
| 37. Can you provide examples of innovative care delivery interventions that have emerged from the [model]? | |
| 38. What supports are in place to ensure effective communication with individual patients and their caregivers? Prompts: interpretation services; supportive vs shared decision making. | |
| 39. In your opinion, what key skills and competencies are crucial for health professionals working within health care teams operating in this [model] Prompts: such cultural competency training, screening for social needs in trauma informed way. | |
| 40. How has the use of technology and data analytics been integrated into your health care team’s practices? - What impact has it had on patient outcomes? | |
| 42. Do you feel you use resources like staff time, and medical care more effectively under this model? - Can you explain why you feel that way? | |
| General Impressions of Model (note: skip any that have already been answered) | |
| 43. In what way(s) do you think providing care under this [model] is better or worse for patients? | |
| 44. How do you perceive the impact of [name/type of] model on the quality of | |

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| patient care compared to traditional fee for service? | |
| 45. In your experience, what specific aspects of patient care have been positively influenced by the [model]? -How does it compare to services provided under fee for service? | |
| 46. Do you think providing care under this [payment model] is better for health care professionals? Please explain your answer. | |
| 47. From your experience, what recommendation would you provide for further enhancing the effectiveness of new models in promoting high-patient-centered care? | |
| 48. Do you have any other thoughts on anything we discussed that you would like to share? | |

5. Wrap-up

Thank you for your time and sharing your experiences and views. Please let me know if you would like to receive the \$100 gift card and if so, I just need to make sure I have the correct address.

- [Confirm proper name]
- [Confirm proper mailing address]

If you have any questions or concerns, please contact [Melanie Phelps][Aalaya Gurram]

Would you be willing to do a written or video testimonial about your experience? Y or N

Would you be willing to help recruit a medically complex patient who has benefited from the extra support and services provided by care team members through the ACO?

Contact Information

Melanie G Phelps, principal investigator, melanie.phelps@heart.org; 919-306-5123

Aalaya Gurram, research assistant, Aalaya.gurram@heart.org; (972) 467-1291



Exhibit D—The Patient and Family Caregiver Study Participants

| Study Participant Overview | ChatGPT Technical Description | ChatGPT Simplified Description |
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| <p>P1 is a Pentecostal preacher from eastern NC, and his wife, C1, also a Pentecostal preacher in the same church, is his caregiver. P1 formerly sold insurance. Both are in their 70s, on Medicare, and enjoy singing, playing music, and preaching in their Eastern NC church. P1 plays guitar, mandolin, and banjo, although he can no longer play banjo because it is too heavy for him. C1 plays piano, organ, and bass. Unfortunately, P1 has several health issues that get in the way of doing the things he loves to do. He has been in and out of the hospital for congestive heart failure, he's had prostate cancer, and frequent urinary tract infections. In fact, the first interview had to be postponed for a few weeks because his health took a turn for the worse, and he was hospitalized. P1 and C2 are a delightful couple and enjoy talking about their health care experience with their ACO. They are especially fond of and grateful to their care manager (T2).</p> | <p>P1 and C1's experience with their ACO reflects a comprehensive, compassionate, and patient-centered approach to healthcare. The ACO's proactive care coordination, accessibility, affordability management, and strong communication contribute to their overall well-being and satisfaction with their healthcare journey.</p> | <p>P1 and C1 are happy with their healthcare because their ACO gives them lots of help, listens to their needs, and makes sure they get good, affordable care.</p> |
| <p>P2 is a widowed, elderly White woman who lives by herself in rural NC. She is fortunate that at least one of her 4 children lives nearby. P2 worked in the local textile mill for 35 years, and when the plant closed, she worked in social services for the next 10 years until she was 68. She quit her job when her husband got sick so she could take care of him. P2 loves to talk and visit with family. She used to like to read and do puzzles but now she watches more TV and uses her iPad. She no longer drives, but her children help with her transportation needs. She doesn't walk very well and uses a rollator, although one of her goals is to be able to walk without the rollator. P2 suffers from COPD, CHF, diabetes, and she also has kidney and thyroid issues. She's also had cataract surgery. Her biggest health</p> | <p>P2's care under the ACO is characterized by comprehensive medical management, effective communication and coordination among her healthcare providers, accessibility to necessary services, and personalized attention that respects her preferences and goals. Her experience highlights the benefits of integrated care</p> | <p>P2 gets great care with her ACO, which means her doctors work well together, listen to her, and make sure she gets the services she needs.</p> |

| Study Participant Overview | ChatGPT Technical Description | ChatGPT Simplified Description |
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| <p>scare occurred in 2016 when she couldn't breathe. She called the ambulance and went to the nearest hospital where she stayed for 6 weeks followed by a month in rehab. She continues to be admitted to the hospital for breathing issues (she had been in the hospital 8 times between December and February for breathing issues and she was in last August due to a shingles reaction). She is currently on Medicare and gets her care through an ACO.</p> | <p>models in managing complex health needs for elderly patients.</p> | |
| <p>P3 is a 62-year-old woman from Delaware. She formerly was a custodian for a county, where she cleaned various buildings. She says that she "enjoyed her job very much but resigned in 2010 due to disability from cancer and other ailments," which makes it difficult for her to breathe. She has asthma and other lung issues such as pulmonary fibrosis as well as diabetes, but breathing is her main concern. She had to pause frequently during the interview to cough and her breathing was clearly distressed. P2 said she used to love to go outside as she enjoyed the outdoors, but her breathing issues have made that difficult. She now likes to color. She is on Medicaid and receives her care through an ACO.</p> | <p>P3's care under the ACO is characterized by effective communication, accessibility through telehealth, comprehensive coordination of specialists, support for social needs, and a strong emphasis on patient-centered care. The involvement of her PCP and chronic care manager ensures that her complex health needs are managed with empathy and efficiency, despite frequent health challenges</p> | <p>P3 has a good experience with her ACO because they use technology to help her keep in touch with her doctors, and they take care of both her health and social needs.</p> |
| <p>P4 is a 77-year-old retired white female who lives in the greater Washington DC area. She is married with two children, and she retired 3 years ago after working in health policy for 35 years. P4 is fond of reading and socializing with her friends. She is a breast cancer survivor, suffers from anxiety, and has had two knee replacements but she currently is in reasonably good health, although she is experiencing temporary mobility issues due to a recent knee replacement. She is on Medicare and gets coverage from her former employer (Federal Employee Health Program). P4 receives her care through an ACO-like arrangement.</p> | <p>P4's experience with her ACO under a total cost of care model is characterized by comprehensive, coordinated, and patient-centered care. The integration of services, effective communication, and strong provider relationships contribute to her high satisfaction with the care she receives.</p> | <p>P4 likes her ACO because everything is well-organized, her doctors communicate well, and she feels cared for.</p> |
| <p>P7 is a 64-year-old retired federal government employee living in a retirement community with her sisters and has two children</p> | <p>P7's experience highlights the importance of a supportive</p> | <p>P7 finds her ACO helpful because they have a strong</p> |

| Study Participant Overview | ChatGPT Technical Description | ChatGPT Simplified Description |
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| <p>(son and a daughter). She navigates life with several health challenges. She reflects, "I was diagnosed as diabetic in the late 40s. I always went to the doctor and had a physical checkup, and they never said I was pre-diabetic." Over the years, she also faced respiratory issues and discovered a problem with her aortic valve, eventually requiring surgery. Post-surgery, complications like pneumonia and the need for oxygen further underscored her health journey. She admits, "It was hard to wrap my head around the idea that I might have to have my valve replaced in 10 to 15 years."</p> | <p>healthcare team, proactive management of chronic conditions, patient education, and advocacy in navigating healthcare decisions.</p> | <p>healthcare team that helps her manage her health conditions and educates her about her choices.</p> |
| <p>P8 is a 60-year-old woman from West Virginia who left home at 13 and got married at 17. She is a widow. She is currently learning to walk again after a severe fall. Her family, mainly her cousin, play an essential role in her life, providing her with much-needed support. Prior to the deterioration of her health, she enjoyed gardening, cooking, flower arranging, crocheting and painting, but her physical limitations and ongoing health issues have made it difficult for her to continue these activities. Her health issues include diabetes, osteoporosis, osteoporosis, osteoarthritis and severe hip dysplasia, which led to mobility issues and significant weight gain (~200 lbs. in 6 months). Despite these obstacles, she remains determined to regain her independence. Until recently, her history with the health care system was unfavorable. Her experience, however, improved with the ACO, and she speaks highly of her current care team: "Whenever I needed something, my doctor was there. They were trying to force me into a nursing home, but the doctor talked to me about losing my leg and he tried to get help in the form of therapy. He got food and therapy brought into my home for me. He had 13 nurses here checking in on me and social workers. I have the best team I can get."</p> | <p>P8's ACO provides a holistic and patient-centered approach to care, ensuring she receives comprehensive medical, emotional, and practical support tailored to her needs. This integrated care model not only addresses her health issues but also enhances her quality of life and supports her journey towards greater independence.</p> | <p>P8's ACO helps her with all her medical and emotional needs and supports her independence.</p> |
| <p>P9 is a 36-year-old widowed mother of 3 kids under the age of 10, she has Medicare due to disability as she has been gradually losing her hearing since 2008. She is Black. She lives in Pittsburgh, PA. A few years ago, her husband had a lung</p> | <p>P9's care from her ACO is characterized by comprehensive primary care, proactive management of</p> | <p>P9's ACO gives her great primary care, helps with mental health, and makes it easy for her to access services, which has</p> |

| Study Participant Overview | ChatGPT Technical Description | ChatGPT Simplified Description |
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| <p>infection, which turned to strep, which progressed to meningitis, and then septic shock. She and her kids watched as his health quickly deteriorated, and he died. While she previously also suffered from depression, since experiencing her husband's death, she began suffering from debilitating anxiety as well. The loss of his income has the family on Medicaid, so she is on Medicare and Medicaid. She gets her Medicare through a Medicare Advantage plan. P9 is an optimistic person, who loves the outdoors and adventure, but everything changed once she lost her husband. His tragic death resulted in debilitating anxiety, which compounded her depression and her persistent fear of losing her hearing. "A lot has changed since I lost my husband. I became scared—scared of what could happen."</p> | <p>mental health and social needs, convenient access to services including telehealth, clear and respectful communication, and financial accessibility. This holistic approach has significantly improved her health outcomes and overall quality of life, reflecting a model of patient-centered care that addresses both medical and personal aspects of her well-being.</p> | <p>improved her health and life quality.</p> |
| <p>P10 is an African American male in in his late 60s who lives near Baltimore, MD. He is on Medicare and has a supplemental policy, and he receives most of his care through an ACO. He is a retired corrections officer and owned and managed a property management company but his poor health has forced him to transfer most of his properties and remaining management responsibilities to his son. He says that his health has been bad for so long that his social life is going to the doctor. He also makes time for church. His ability to do things like go to museums is hampered by his inability to walk for prolonged periods. His health issues include back problems, gout, rheumatoid arthritis, kidney disease, and diabetes. He has neuropathy and is on diabetes medicines to help with weight loss.</p> | <p>P10's care through the ACO is characterized by comprehensive management of his chronic conditions, effective communication and coordination among his healthcare team, personalized support for both medical and non-medical needs, and a strong emphasis on building trusting relationships with his providers. This approach ensures that P10 receives holistic, respectful, and responsive care tailored to his specific health challenges and personal preferences.</p> | <p>P10 gets good care from his ACO with helpful communication, support for his health needs, and a focus on building trust with his doctors.</p> |
| <p>P11 is 64-year-old women who was born in Dallas, lived in South America growing up and eventually went to Connecticut for college. She eventually moved to Virginia where she found herself working at a hotel before moving to Bethesda, Maryland. In 2019, she decided to take a severance package</p> | <p>P11's ACO provides her with a well-rounded and patient-centered approach, addressing her multifaceted health issues with a supportive and</p> | <p>P11's ACO helps her with all her health issues and offers good support for her family and doctors.</p> |

| Study Participant Overview | ChatGPT Technical Description | ChatGPT Simplified Description |
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| <p>and retire to take care of her family. P11's health journey has been marked by significant trials. Despite these challenges, she remains remarkably optimistic. "I am pretty lucky," she says, reflecting on her experiences. Her medical history is complex, with treatments for cancer and gastrointestinal issues impacting her kidneys. In the spring of 2021, P11 started experiencing shortness of breath and passed out and hit my head while walking my mom's dog." After a series of tests, doctors discovered a peptic ulcer and severe aortic stenosis. P11 had a blood transfusion, and her cardiologist recommended a valve replacement, which she had before starting cancer treatment. Her battle with health issues didn't end there. She recalls, "I have a bit of high blood pressure, and my primary care doctor wants to put me on statins for cholesterol." P11 has a family history of heart disease on her father's side and cancer on her mother's. "My kidney numbers are bad, but it doesn't affect me much," she explains. "It's a trade-off between protecting my kidneys and preventing the tumor from growing." P11's experience with the health care system has been mixed, but with respect to her current team, despite ongoing challenges with communication with external providers, she says: "I feel like my healthcare team is supportive. I'm comfortable with them and trust their recommendations. Sometimes it takes time to find the right team, but it works."</p> | <p>coordinated healthcare system. The emphasis on personalized care, family support, and proactive health management reflects the high-quality care she receives.</p> | |
| <p>P12 is a 69-year-old resident of Baltimore who was raised by her mother but also remained close to her father. She is widowed and has three children with her husband. Unfortunately, she lost one of her sons due to a brain aneurysm. She is taken care of by her other son and daughter. She lives with her brother, and her granddaughter lives nearby, bringing her children to visit often. In her professional life, P12 worked two decades to the printing industry, crafting cups and plates until health challenges necessitated her retirement in 2005 as she stated how "I stopped working with a lot of difficult</p> | <p>P12's care from her ACO is characterized by its thoroughness, patient-centered approach, and strong support network, allowing her to manage her health effectively and live a fulfilling life.</p> | <p>P12 gets thorough, patient-focused care from her ACO, which helps her manage her health and live well.</p> |

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| <p>problems going on health wise.” P12 had a liver transplant in 2018, and diligently manages her post-transplant care, saying that her health is paramount. P12 finds strength in her faith and community activities, including water aerobics with her grandchildren.</p> | | |
| <p>P13, a veteran, and his wife, C3, live in the Pittsburgh, PA area. They are both retired and have 3 grown children and multiple grandkids that still live in the area. They enjoyed going on vacation and spending time with the family. P13 formerly worked at a local supermarket and later as a nurse’s aide until 2008 when he was forced to retire for health reasons. P12 was diagnosed with amyloidosis, which led to debilitating heart and lung issues. He has been in and out of cardiac and pulmonary rehab, although he is currently back in pulmonary rehab. P13 has a Medicare Advantage plan. P13’s wife, C3, also worked but also has been his primary caregiver since that time. She retired 7 years ago, but still works part time and takes P13 to rehab twice a week and other appointments. She says that her caregiving duties can be very challenging and draining. P13 says that his health issues get in the way of doing what he likes to do and says: “Sometimes I feel like I am useless because I can’t do things I used to do like taking care of the house, the car, etc.” C3 added: “I’ve learned to do things that he (P13) used to do. I am pretty independent and don’t like to call folks if I don’t have to.”</p> | <p>P13 and C3 receive integrated, compassionate care through his PCP’s practice within the ACO framework. The emphasis on coordination, accessibility, and patient-centered communication has evidently contributed to a positive healthcare experience despite P13’s complex medical needs.</p> | <p>P13 and C3 receive compassionate care from their ACO, with good coordination and communication from their doctors, even with GG’s complex needs.</p> |
| <p>C2 is 76-year-old caregiver for her husband who is 84, and has multiple health issues includes diabetes, glaucoma, mobility issues, and multiple knee replacements. She says, “His main health issue is really his diabetes. We are trying to do our best to control it. It is hard for him because he is an old person. It is hard to change his mind set on this. I try to keep the blood flow in his right leg. The insulin kind of controls diabetes and he eats food. Due to lack of movement, it makes it hard for him to go to the bathroom.” As for how she deals with her caregiver</p> | <p>The care provided through the ACO is comprehensive, well-coordinated, and person-centered, with a strong emphasis on accessibility, communication, and support. The C2 and her husband benefit from a robust support system and high-quality medical care, although there is room for</p> | <p>For C2’s husband, the ACO gives comprehensive care with good communication and support, but there is still room to improve mental health support and ensure all specialists provide high-quality care</p> |

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| responsibilities she says: "It takes a toll on you sometimes. It's a lot." | improvement in mental health support and ensuring all specialists meet the same high standards of care. | |