, 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

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 servic e.

Patients and Caregivers

Patients and family caregiver interview s 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 medi cally 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. Th ose who were under 65 were on Medicar e due to d isability 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

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person and she understands what is important to me."

- When asked what he likes best about his care, P 10 talks fondly of his PCP: "It's always good to see her. We ask about each other's families. We have a personal nN^ArVcaoUVk AaL AnN ca A nor aA'N IAoVo %sn nN^ArVcaoUV better. "

x A team of health care professionals who provide enhanced care and support.
  - According t o 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 rUN VarncLsJNL cS rUN JAnN 'AaATNn rUncsTU UVo - -,o cS JN 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."
x 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.

- P2 shared that “sometimes, I’m in there for an hour. I never feel rushed and I get the whole 9 yards.”
- 0N NJrVaT ca UNn UNA^rUJAnN \csnaN{ - AkknNJVArNo rUN k "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-

manner that is convenient for her and she frequently utilizes telehealth for non

- 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. -ncxVLNno JAaacr]acy NxNn{rUVaT TcVaT ca csroVLN cS rUN c 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
  - µ3UN JAnN kncxVLNL I{ rUN ‘cLN^ Vo oskNnVcn msA^Vr{ cS JAr 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 assist (t)9 (or) n1 (t)9 (n 1)1.2 1e5495c c a a (e)-mn ttisr6§e6]7Y4ã~

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

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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 wa nted 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 resul (os)3.1u5.8 (r)1.8 (s)3 rndbdsal1td

Suggested Improvements	Supportive Quotes

Suggested Improvements	Supportive Quotes
Improve data sharing.	- “

- o “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
- o “Fee for service doesn’t prioritize preventive care or encourage active participation in your own health care.” – community health worker, Arizona

x Better for patients and providers
- o “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
- o “[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

x Less waste
- o “There is [a lot] of wasted, unnecessary procedures and testing and a lot of money wasted in fee for service.” – nurse care manager, Massachusetts
- o “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 ab(a)2.7 (d)-2.7 (v)3.3 b3-0.7 (p)6.2

Exhibit A—Literature Review Bibliography

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members in value-based arrangements. The learnings from this research will be used to advocate for improving health care experience, services and outcomes for NxNn{caN 3c IN N^VTVI^N rc kAnrVJVkArN orsL{ kAnrVJVkAaro ‘s value -based arrangement and be or care for a patient(s) who are medically complex.

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

Patient Background Information Including Goals of Care	
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?	
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	
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?	
A a {c s InV N { LNoJnVIN {c s n 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.	c x N n A ^ ^
Care Team Interactions and Care Coordination/Management	
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?	
6. Who do you see or talk to most often for your health and other care? Prompts: :U c V o r U N n o r k N n o c a {c s r n{ r c o N N with a health -related issue?	
7. How long and/or how often do you interact y V r U r U V o k N n o c a A a L U c y o A r V o N L A n N {c s with your interactions?	
8. Do you see any other doctors or providers, like nurses, social workers, pharmacists, care managers or navigator, community health workers, etc.?	

9. How long and/or how often do you interact
yVrU rUVo kNnoca AaL Ucy oArVo NL AnN {cs
with your interactions?

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

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?	
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?	
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?	
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.	
24b. If costs have been a barrier, ask: “Do your UNA^rU JAnN kncxVLNno ycn] yVrU {cs rc aL assistance or alternative treatments that are more affordable?	
Person- Centeredness/Communication	
25. How respectful and responsive is the care you receive? Prompts:	

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.

   x ‹ c a n ‘ k n c k N n a A ‘ N ›
   x ‹ c a n ‘ k n c k N n ‘ A V ^ V a T A L L n N o o ›

   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 car e 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.

used to advocate for improving health care experience, services, and outcomes for

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

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-

11c. Are there any patient groups or populations that pose unique challenges to care coordination? - How are they handled?	
12a. How are transitions of care managed? Note : Where applicable, ask about pediatric to adult care transitions.	
12b. Who on the health care team is responsible for transitions of care management?	
12c. How do you evaluate the effectiveness of care transition management services?	
13. What patient populations pose o k N J V J J U A ^ ^ N a T N o r c r n A a o V r V c a o c S J A n N management? - How are they handled?	
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?	
Equity	
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? *(Alt: How do you ensure that historically marginalized populations (racial & ethnic minorities; those with disabilities; those in rural areas; and those with low SES))* L N a V r V c a c S U N A ^ H e a l t h N m s V r { 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.	

16. How does your organization ensure

Practice, Skills, and Culture (note —if time is running out, skip to last section)

patient care compared to traditional fee for service?	

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aspects of patient care have been

Study Participant Overview	ChatGPT Technical Description	UAr -3 1V‘k^V NL NoJnVkrVca
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.	models in managing complex health needs for elderly patients.	
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 dif Js^r Scn UNn rc InNArUN 1UN UAo AorU‘A AaL crUNn ^saT VoosNo osJU Ao ks^‘caAn{ IncoVo Ao yN^^ Ao LVAINrNo Isr 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		

Study Participant Overview	ChatGPT Technical Description	U A r - 3 1 V ‘ k ^ V N L N o J n V k r V c a
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.		

Study Participant Overview	ChatGPT Technical Description	UAr -3 1V‘k^V NL NoJnVkrVca
and retire to take care of her family. P11’s health journey has INNa ‘An]NL I{ oVTaV JAar rnVA^o NokVrN rUNoN JUA^^NaTNo oUN remains remarkably optimistic. "I am pretty lucky," she says, nN NJrVaT ca UNn NzkNnVNaJNo Nn ‘NLVJA^ UVorcn{ Vo Jc‘k^Nz 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		

Study Participant Overview	ChatGPT Technical Description	UAr -3 1V‘k^V NL NoJnVkrVca
problems going on health wise.” P12 had a liver transplant in 2018, and diligently manages her post -transplant care, saying rUAr UNn UNA^rU Vo kAnA‘csar - aLo orn community activities, including water aerobics with her grandchild ren.	NaTrU Va UNn SAVrU AaL	
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		

Study Participant Overview	ChatGPT Technical Description	U A r - 3 1 V ‘ k ^ V N L N o J n V k r V c a
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.	