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

Melanie G Phelps, DrPH, JD, Principal Investigator and Senior Advocacy Advisor, Health System Transformation, Federal Advocacy, American Heart Association

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Background

This research about the ACO experience and its potential to improve the
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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 Id N a r V € J A T V c a 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:

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[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 US 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.

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 service s, which are essential to building trust.

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 cost s and cost transparency . Are attempts made to incorporate affordability into decision making when possible? Patients and their family caregive 6ea incocntimis2.4 (ra)2. ( )-5.4 18xl(m)-5.watnci72.4 (i)-cc3i7(us)3C(he)1.8iden ih(i)-2.2 (n) aftailel

- According to P13 ’s wife/caregiver , C3: “[

- P3 praised her PCP 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 pati wii

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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

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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 oskNnVcnœ msA^Vr{ cS J 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.	- “

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members in value-based arrangements. The learnings from this research will be

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?	
Œ™ Aa {cs InVN•{ LNoJnVIN {csn cxNnA^^ 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.	
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: :Uc Vo rUN €nor kNnoca {cs rn{ rc oNN with a health -related issue?	
7. How long and/or how often do you interact yVrU rUVo kNnocaš AaL Ucy oArVo€NL AnN {cs with your interactions?	

9. How long and/or how often do you interact
yVrU rUVo kNnocaš 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:	

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-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?	

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?	
Œ•™ a {csn NzkNnVNaJNš yUAr okNJV€J aspects of patient care have been kcoVrVxN^{ Va•sNaJNL I{ rUN ¬`cLN^- -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

Exhibit D—The Patient and Family Caregiver Study Participants

Study Participant Overview	ChatGPT Technical Description	U A r - 3 1 V ` k ^ V € N L N o
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		

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 LVAINrNoš 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^^NaTNoš oUN remains remarkably optimistic. "I am pretty lucky," she says, nN•NJrVaT ca UNn NzkNnVNaJNo™ Nn `NLVJA^ UVorcn{ Vo Jc`k^Nzš 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™ -‰Š €aLo community activities, including water aerobics with her grandchild ren.	ornNaTrU 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.	