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## “You Are the Key”: A co-design project to reduce disparities in Black veterans’ communication with healthcare providers

Anna M. Barker

*VA Center for Healthcare Organization & Implementation Research (CHOIR), Bedford, MA*

Renda S. Wiener

*VA Center for Healthcare Organization & Implementation Research (CHOIR), Boston, MA*

Dave Crocker

*U.S. Navy Veteran*

Makayla Dones

*VA Center for Healthcare Organization & Implementation Research (CHOIR), Bedford, MA*

Oluwabunmi Emidio

*VA Center for Healthcare Organization & Implementation Research (CHOIR), Boston, MA*

*See next page for additional authors*

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### **Cover Page Footnote**

We wish to acknowledge the 5 Veteran co-designers (including author Dave Crocker) of the “You Are the Key” booklet, as well as the members of the Lung Cancer Screening stakeholder group led by Dr. Jeff Whittle, Medical College of Wisconsin and Clement J Zablocki VA Medical Center (Milwaukee).

### **Authors**

Anna M. Barker, Renda S. Wiener, Dave Crocker, Makayla Dones, Oluwabunmi Emidio, Abigail N. Herbst, Jenesse Kaitz, Lauren Kearney, Danielle Miano, and Gemmae M. Fix

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Anna M. Barker, *VA Center for Healthcare Organization & Implementation Research*, [anna.barker@va.gov](mailto:anna.barker@va.gov)

Renda S. Wiener, *VA Center for Healthcare Organization & Implementation Research*, [renda.wiener@va.gov](mailto:renda.wiener@va.gov)

Dave Crocker, *U.S. Navy Veteran*, [dave.crocker@verizon.net](mailto:dave.crocker@verizon.net)

Makayla Dones, *VA Center for Healthcare Organization & Implementation Research*, [Makayla.Dones@va.gov](mailto:Makayla.Dones@va.gov)

Oluwabunmi Emidio, *VA Center for Healthcare Organization & Implementation Research*,  
[Oluwabunmi.Emidio@va.gov](mailto:Oluwabunmi.Emidio@va.gov)

Abigail N. Herbst, *VA Center for Healthcare Organization & Implementation Research*, [14aberbst@gmail.com](mailto:14aberbst@gmail.com)

Jenesse Kaitz, *VA Center for Healthcare Organization & Implementation Research*, [Jenesse.Kaitz@va.gov](mailto:Jenesse.Kaitz@va.gov)

Lauren Kearney, *VA Center for Healthcare Organization & Implementation Research*, [Lauren.Kearney@va.gov](mailto:Lauren.Kearney@va.gov)

Danielle Miano, *VA Center for Healthcare Organization & Implementation Research*, [dam677@nyu.edu](mailto:dam677@nyu.edu)

Gemmae M. Fix, *VA Center for Healthcare Organization & Implementation Research*, [gemmae.fix@va.gov](mailto:gemmae.fix@va.gov)

### Abstract

Interventions are needed to overcome a key barrier to patient-provider communication, namely that patients hesitate to participate in clinical conversations because they believe their expected role is to be passive. This expectation is reinforced for veterans, who replicate their experience of military hierarchy in the patient-provider relationship. Black veterans, moreover, encounter structural racism that compounds this power imbalance. This paper describes a co-designed intervention to empower Black veterans to talk with providers, using shared decision-making (SDM) for lung cancer screening (LCS) as an exemplar. We worked with a diverse group of 5 veterans to develop materials that normalize participating in clinical conversations. We then interviewed 10 Black veterans selected from a national sample to assess the booklet’s impact and contextual factors. The co-design team produced a 30-page booklet that includes veteran narratives describing positive clinical interactions, as well as didactic information about SDM and LCS. We identified four themes related to Black veteran participants’ healthcare experience: (1) they want truthful and complete information exchange with providers they know; (2) they often feel their concerns are disregarded; (3) poor communication worsens medical treatment; and (4) they are confused and angry about treatment in clinical encounters that they feel are racist. The booklet was described as interesting and informative. The veteran narratives in the booklet particularly resonated with readers. Assessment of the booklet’s overall impact on planned engagement with providers varied. Co-designed materials that normalize participation in clinical encounters can play a role in reducing disparities in patient-provider communication.

### Keywords

Patient-centered care, patient engagement, health disparities, equity, communication, co-design

### Background

Communication between patients and healthcare providers is a social interaction. As such, it is subject to the same social cues and expectations as any other form of communication. These expectations, often based on experience,<sup>1</sup> can either help or hinder the interaction’s success. One barrier to successful patient engagement in interactions with providers is the patient’s perception of their role in the clinical encounter: what has been described as an inherent provider-patient power differential.<sup>2</sup> Patients may feel, for example, that it is *normal* to be passive and let providers make decisions; they fear negative consequences if they are seen as inflexible or

troublesome; and they may perceive that *good* patients benefit from lack of conflict in the encounter, or that asking questions would indicate a lack of trust or respect.<sup>2,3</sup>

These perceptions may be particularly enhanced for military veterans participating in clinical encounters at the US Department of Veterans Affairs (VA), the largest nationally integrated healthcare system in the US. Veterans bring their active military experiences of hierarchy and power differentials to the VA medical visit.<sup>4</sup> For Black veterans, this effect is compounded by the impact of structural racism and individual bias experienced in clinical encounters.<sup>5,6</sup>

In fact, lack of participation in the clinical encounter is particularly evident among Black patients.<sup>7,8</sup> White patients self-initiate more active participation than nonwhite patients – asking questions, expressing concerns and negative feelings, and being assertive (stating opinions and preferences).<sup>9</sup> Black men report they are more likely to defer to authority and less likely to experience information exchange or have their concerns validated, further contributing to their sense of power imbalance.<sup>3</sup>

This perceived power differential is a barrier to ideal healthcare communication such as shared decision-making (SDM), the process through which patients and providers share information and deliberate together before making medical decisions.<sup>10</sup> SDM should occur before deciding on lung cancer screening (LCS), for example, because both potential benefits and harms from LCS are high.<sup>11,12</sup>

Lung cancer is the leading cause of cancer death among military veterans, and early detection through LCS can decrease deaths by 20%.<sup>13</sup> On the other hand, LCS also exposes all veterans to potential harms (eg, radiation exposure, emotional distress, physical complications from biopsies). Notably, Black Americans have the highest lung cancer mortality rate compared to the rest of the US population. Black men have 1.28 times the incidence and 1.22 times the risk of lung cancer in comparison to white men, even though smoking rates are similar.<sup>14</sup> They have been found to derive the greatest mortality benefit from LCS,<sup>15</sup> but Black people are less likely to participate in LCS.<sup>16,17</sup>

Ideally, in clinical situations such as LCS – where trade-offs exist that individuals value differently<sup>18</sup> – providers contribute clinical information, patients contribute information about their lives, and they decide together through the collaborative process of SDM. Yet high-quality SDM for LCS rarely occurs in practice.<sup>11,19,20</sup> Our research team seeks to encourage SDM for LCS at all levels of the VA healthcare system, including removing barriers at the patient level.

While some patients do not want to be involved in SDM at all, or opt to defer final decision-making to their doctor, 96% of the general US public expressed in a national survey a preference to “be offered choices and to be asked their opinions” about medical options.<sup>21</sup> It may therefore be that patients often want to take an active role in SDM but are concerned about the consequences.<sup>3</sup> Thus, while SDM is described as promoting patient empowerment,<sup>22</sup> patients must first reach a level of empowerment that will enable them to participate in SDM.

Interventions that are co-designed by peers may be particularly effective at promoting empowerment.<sup>23</sup> Co-design is a method associated with participatory action research (PAR), an approach that enables social action and

fosters empowerment. We worked with veterans to co-design materials that empower veterans to participate in clinical conversations, and especially to participate in SDM for LCS. Through PAR, the people who are most affected by the research play a material role; they know their own experience best and have an interest in making improvements.<sup>24</sup> This parallels our goal to recognize veterans’ expertise, invite them to participate in the project in a material way, and to recognize them as partners in their own care.

Through co-design, stakeholders work together to create a new product.<sup>25</sup> Co-design is recommended to address the need for culturally appropriate patient education materials for subpopulations,<sup>14</sup> making it well suited to develop LCS educational materials for Black veterans. Additionally, veterans are a distinct, cohesive peer group that uses similar descriptive terms (e.g., *battling*) when describing communication with providers,<sup>26</sup> which lends itself well to culturally tailored messages.

Our materials included the promotion of SDM for LCS as an exemplary patient-provider interaction, but we expected the overall framework of patient empowerment to be more universally applicable. Moreover, given the enhanced power differential between Black veterans and their providers, as well as the benefits of LCS for - and lack of participation in SDM for LCS among - Black veterans, we postulated that materials we developed might have a pronounced impact on this population.

We sought to create culturally tailored, informative and engaging content for veterans. By including Black veterans in co-design, we intended to increase the likelihood that the educational materials developed would resonate with other Black veterans. Phase 1 describes our co-design process and the resulting booklet. Phase 2 describes the sentiments of Black veterans when they reflected on previous encounters with providers and medical staff. It included our pilot test, exploring the impact of the booklet on Black veterans receiving care at the VA. We considered the booklet’s relatability, cultural relevance, and influence on behavior as contextual factors.

## Phase 1 – Co-Design

### *Methods*

In our Vets PARTiCIPATE study (Veterans Participatory Action Research to Co-design Innovative Patient Activation Tools for Engagement), we used social norms theory<sup>27</sup> as a foundation for developing patient-facing materials that address individual misperceptions about what is expected of a patient in the clinical encounter. Social norms theory focuses on the role that peer influence can play in individual behavior; interventions counter perceived behavioral norms with messages that promote healthy behavior. We challenged the prevailing assumption

**Table 1: Co-Design Steps and Associated Tasks**

Step	Tasks
Recruitment	Outreach; information sessions; formal interviews
Foundation & Information Collecting	One-on-one meetings with Veteran co-designers; exchange information; prepare introduction to group
Running Co-Design Groups	Introductions; message development; platforms & distribution channels; putting it all together
Prototyping & Review	Create prototype; review content, layout, design elements; create final draft
Feedback & Evaluation	Share final draft with knowledgeable outsiders for final review; incorporate suggested revisions; final comments from each co-designer; agree on final product

that a patient's lack of interest in participating in SDM is a personality trait, and instead promoted positive attitudinal change. Our materials explicitly give veteran patients permission to challenge the patient-provider hierarchy by expressing their values and preferences. The study conducted October 2020–September 2021, used principles of co-design, working with a diverse group of five veterans to develop the patient materials. This study was approved by the VA Bedford Research & Development Committee. Here we present the five steps of our co-design process. (See Table 1.)

**Recruitment.** We used snowball sampling to recruit veterans to our co-design team, beginning by reaching out to our research center's network of veterans interested in research activities. We conducted two information sessions, which allowed us to both introduce the project to interested veterans and observe them in a group situation. We then interviewed all veterans who expressed interest in joining the team, with the intention of ensuring that team members possessed clear communication skills and represented diverse perspectives. We recruited seven veterans to account for attrition, with a goal of at least five participating throughout co-design. The veterans we retained were treated as consultant members of the co-design team and paid hourly for their contributions.

**Foundation & Information Collecting.** Two team members (A.B. and A.H.) met with each veteran co-designer individually for relationship building and information exchange, and to prepare each veteran for working with the group. We gave veterans prompts to share *three things about me* and suggested they prepare a response to each prompt as an introduction at the co-design group session. All team members, including researchers, introduced themselves in this way – rather than by their professional credentials – to flatten the hierarchy among the full team.

**Running Co-Design Groups.** The full team met for two hours every other week over Zoom, in the early evening to accommodate veterans' schedules. In the weeks between sessions, the research team met to debrief and prepare for the next meeting. At each session, the full co-design team

worked through the process of materials design: developing the messages (mapped to evidence-based health communication barriers); considering platforms and distribution channels for the final product; and putting all content together in one envisioned product. The sessions were facilitated by a member of the research team (A.B.) with idea generation coming from the veteran co-designers. Veterans and researchers paired up to create the narratives, described below, with the veteran dictating the storyline for the researcher to draft.

**Prototyping & Review.** Once the final product was drafted, the research team met with a graphic designer to develop a prototype. At a co-design session, the graphic designer shared the prototype to gather input on all aspects of the final design, including typeface, layout, photographs, and other graphical elements. All team members had the opportunity to provide comments over Zoom or by email to ensure they were satisfied with the final product.

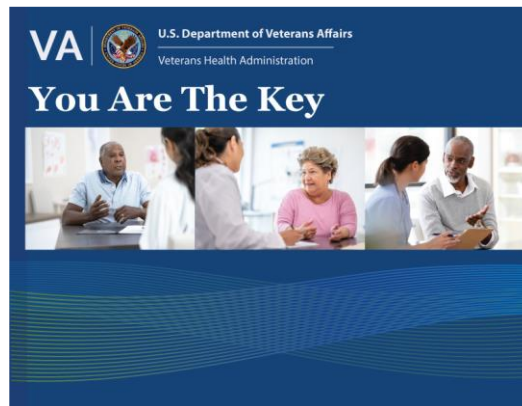
**Feedback & Evaluation.** We shared the prototype with a group of veteran stakeholders who advise on LCS research.<sup>28</sup> We met virtually with this team of four veterans, a communications researcher, and a physician researcher for feedback. The group's suggestions were incorporated in a revised draft. The full co-design team and graphic designer then met one last time, with each veteran making final comments and all members of the team participating in final content decisions.

### **Results: “You Are the Key” Booklet**

The final product is a 30-page booklet with the title and theme of “You Are the Key” – a title selected by the veteran co-designers to attract attention and engage other veterans in the content (Figure 1). The veteran co-designers envisioned the booklet as something that a veteran might pick up in the waiting room, but an [online version](#) is also available to increase accessibility.

The booklet includes an introduction from the veteran co-designers, an explanation of social cues in the patient-

**Figure 1. “You Are the Key” Booklet**



provider interaction, didactic information about both SDM and LCS, opportunities for veterans to reflect about their own communication style, and activities (crossword puzzle, word search) to keep them engaged. Building on the VA’s Whole Health approach to care,<sup>29</sup> there is a page describing Whole Health and another on managing anxiety at medical visits.

One-page narratives are included throughout the booklet – four from veterans and one from a VA physician on the research team (R.W.). The narratives are designed to counter typical assumptions that serve as barriers to patient communication, such as the idea that it is not appropriate for veterans to make requests of providers; that providers do not welcome veteran input; that providers judge veterans who smoke. One narrative tells the story of a veteran who overcame her fear of talking with doctors, and another incorporates the VA’s Whole Health approach. Each narrative has a veteran profile that includes their military branch. They are fictitious but based on the lived experiences of the veteran co-designers on our team.

## **Phase 2 - Pilot Test**

### ***Participants***

We identified a national cohort of Black veterans eligible for LCS (50-80 years old, in good health, currently smoking or having quit within the past 15 years, at least a 20 pack-year total smoking history), with no previous VA LCS as of July 2022, using data from the VA Corporate Data Warehouse.

### ***Methods***

We mailed baseline and follow-up surveys to a random sample (n=200) from our cohort. Survey data analysis is ongoing.

We conducted semi-structured qualitative interviews with a purposeful sample of 10 Black veterans who completed the survey, to better understand their healthcare experience. Interviewers asked veterans about their communication experiences with VA providers, conversations with providers about LCS, and factors that might complicate the conversation such as smoking-related stigma or experiences of racism. Veterans were asked for their reactions to the booklet and interpretation of its overall message.

A research team member with expertise in qualitative methods (A.B., G.F.) led each interview, which was recorded over Microsoft Teams; one to two additional members of the research team (A.D., S.B., L.K., O.E.) took notes. Interviews were transcribed, and a rapid qualitative analysis was performed. Our Institutional Review Board designated this project, conducted in collaboration with VA’s Office of Health Equity, as a quality improvement activity.

### ***Results***

Interview participants ranged in age (63 to 76 years), gender (two female), and geographic location. They had a variety of attitudes towards providers, from *doctor knows best to we work together as a team*. (Table 2.)

We identified four themes related to Black veteran participants’ healthcare experience: (1) they want truthful and complete information exchange with providers they know; (2) they feel their concerns are disregarded; (3) poor communication worsens medical treatment; and (4) they experience confusion and anger about treatment in clinical encounters that they feel are racist. The booklet was described as interesting and informative. The veteran narratives in the booklet particularly resonated with readers. Assessment of the booklet’s overall impact on planned engagement with providers varied. We describe these results below with representative quotes for each.



**Table 2. Participant demographics, representative quotes of attitudes towards providers.**

ID#	Gender	Age	Location	Attitudes Towards Providers
1	M	68	Ohio	<i>"You know better than I do. That's your profession. ...I'm not a doctor. I'm not gonna dispute what you say or what you might advise me to do. I'm cool with it."</i>
2	M	76	North Carolina	<i>"...the doctor I had before was an outstanding individual and I miss him because we got right down to the nuts and bolts of what was expected..."</i>
3	F	63	Ohio	<i>"Sometimes the doctors just need to listen to what you say and consider it. Oh, and I don't know. I seem like I have maybe better experiences sometimes with women. They... pay a little more attention. I think they're a little more meticulous, but that's just me. Experiences I've had."</i>
4	M	65	Oregon	<i>"He's a professional, you know? So I get his opinion first. Then maybe I ask questions. But I don't think I ask too many questions."</i>
5	M	74	Connecticut	<i>"They told me, 'Number one, stop smoking.' I said, 'Well, I ain't gonna do that.' So I told them I'm not gonna stop smoking until I die."</i>
6	M	65	Massachusetts	<i>"I don't really get nervous or nothing like that with those doctors, actually. I look forward to it. I always say I don't want nothing to sneak up on me like cancer or something."</i>
7	M	66	North Carolina	<i>"You always take the doctor's advice because he's there to help you."</i>
8	M	64	Michigan	<i>"I ask a lot of questions and I listen to the advice he gives me, and we come together on a plan. ...Because it's my health, and I know how my body is reacting and everything, and what's wrong with it. So the bottom line is, I know when I need serious help and I know when it's just routine."</i>
9	M	70	Ohio	<i>"I was always trying to fix me myself, but I don't know anything along those lines, you know what I'm saying?"</i>
10	F	72	Nevada	<i>"Old people like me, we want the truth, we want results, but we don't want to be pushed into something that doesn't seem right to us."</i>

### **Black veterans want truthful and complete information exchange with providers they know.**

Several veterans expressed a desire to be given truthful and complete information. One veteran described his provider favorably in this way: *"She told me if you don't stop what you're doing, I don't expect you to be around. She was point blank, and I like that. She tell me what it is."* (ID1) Veterans shared positive experiences of providers who had successfully built a rapport, empowering veterans to offer complete and honest disclosures: *"She just made me comfortable to where I would tell her what was hurting and what was not hurting, and she just – I would get to her and my mouth would open and everything would come out."* (ID10)

### **Black veterans often feel their concerns are disregarded.**

A recurring theme was a feeling by Black veterans that their concerns were dismissed or not validated by their providers, leading to frustration and dissatisfaction: *"Sometimes I'd tell them what my symptoms are, and I felt like they just completely disregarded it. Like I didn't know what I was talking about, but they knew better."* (ID3)

This was enough to make one veteran seek another provider:

*"Now if you're not being heard, that depends on the doctor. Because you have some doctors that – to be quite frank, they don't think you know anything because they went to medical school and everything, and you didn't. But the bottom line is, they don't listen to you when you're telling them something is wrong... and they just treat you like*

*you're dumb.... So that could be the problem right there. When I get a doctor like that, I eliminate it real fast because I get another one."* (ID8)

Similarly, another veteran described her former provider, whom she valued for her communication skills but who had recently retired: *"She listened. My opinion mattered to her. What I felt about my own health mattered to her."* (ID10) This description contrasted sharply with her opinion of her new provider:

*"My new doctor, she's really good, but – maybe it's because she's younger – she's sort of stuck up. That's the only word I can think of... 'We're going to send you down to take this test.' – Without me having any input. ...It's not that she's mean, she's just by-the-book. But just because we're veterans doesn't mean we're not humans."* (ID10)

### **Poor communication worsens medical treatment.**

More than just a source of frustration, when veterans' concerns are not validated it can lead to a lack of medical attention. One veteran described a situation where his provider didn't follow up on his complaint. *"My appointment might last five minutes and I'm right back out the door. I remember one time I went there, my legs were hurting so bad. [I thought she might] offer some tests or something to see what the problem is. Nope. I'm right back out the door."* (ID6) Another veteran ended up in the emergency room before receiving the prescription for antibiotics he had requested. *"Instead of*

*them catching it before it got to the point where it did, I wind up going to the emergency room.” (ID2)*

### **Black veterans experience confusion and anger about treatment in clinical encounters that they feel are racist.**

Some veterans noted that they suspected racism was at the heart of their treatment but weren't sure. “*Yeah, sometimes I felt that. I talked to my providers, and they didn't pay attention to what I was saying...I don't know if it was race or because I'm a woman. I can't tell. I don't know. Or maybe a combination of both?*” (ID3) A veteran with COPD said of his provider, “*Drum beating for this oxygen attention, it just looked like it rained on deaf ears. Because for years, I'm having a situation, having a problem, and she just. I don't know – I don't know if it was racism.*” (ID9) The veteran with pain in his legs suspected that his foot doctor did not want to cut his toenails because he did not want to touch his black feet. “*That's the way it seemed to me anyway, to be honest, and I'm an honest person.*” (ID6)

Other times, veterans were very clear that they were experiencing racist treatment by their providers. One veteran recounted four separate instances of being accused of misusing his pain medication. His account of seeing a urologist for antibiotics reveals the level of hurt and resentment associated with this encounter:

*“Long story short, they didn't have all their facts straight and so that's why I said when I went in there this yoyo just out of the clear blue accused me of coming to the doctor shopping, looking for drugs and it really burned me up big because I'm Black and I don't - very seldom do I use that as an excuse. But it just burned me up that he didn't take time to find out why I was there. That was the first thing out of his, out of his mouth.” (ID2)*

Another veteran was similarly offended about the way he was treated:

*“Racism is in every part of society, you have to realize that. When you go to the doctor, you're going to get second-hand treatment. I went to the doctor one time, and the nurse let the trainees - the ones that stick you in the arm for intravenous – practice on me. She had five students poke me. And that made me so mad...I got mad, and that's when she stopped, and they laughed about it...I had to leave.” (ID8)*

This veteran ended the conversation by highlighting very profoundly the reason why the Black veteran experience in the clinical encounter matters:

*“A lot of people, because we Black, treat us like we secondhand, or nothing but a test tube, and that don't work. That don't work because it angers people. And it also makes them not want to go to the doctor, which is serious business – that could kill them.” (ID8)*

Yet it is possible for the clinical encounter to be an experience of human connection. As one Black veteran

said of his white provider, “*Well, when I look at her, I see a human being. I see somebody that's trying to help me.*” (ID1)

### **The booklet was described as interesting and informative.**

The veterans we interviewed said they found the booklet to be interesting and informative. “*I found it informative, and it wasn't boring.*” (ID2) “*I thought it was very interesting.*” (ID6) While one Veteran said that he had not read the booklet, none shared negative opinions of the booklet. One veteran compared the booklet favorably to other materials she had received from VA:

*“The book is helpful. It puts things in layman's terms so it's understandable. Because I've gotten some papers from VA, and I'm reading them, and I'm going like, what is this? But ‘The Key’ was straight to the point and understandable. And the puzzles and the word search were fun.” (ID10)*

Veterans seemed to understand the main message of the booklet, that it is normal and acceptable for veterans to talk with their providers about their health. One veteran summarized the booklet's message by referring to its title: “*It says ‘You Are the Key,’ in other words you are the key to your own health.*” (ID8) Veterans also mentioned the didactic information about LCS. “*I appreciated the booklet when it told you a little bit about what the lung cancer screening was actually about, because I honestly didn't know anything about that either.*” (ID3) One veteran clearly understood the booklet's message but expressed that he already felt comfortable interacting with his doctor; he therefore focused on the information about LCS:

*“To me it was very informative... The booklet's pretty interesting. I got a lot out of it. Mainly on that lung cancer thing, but that's mostly what that booklet is about. It pertained to me, this book is pretty good for me anyway. But I do ask things, and if I don't understand, I let my doctor know. ‘What do you mean by this,’ and what this test is for, and ‘why should I take this test,’ and stuff like that.” (ID6)*

### **Veteran stories resonated with readers.**

A key feature of the booklet, stories from veterans describing their interactions with providers, resonated strongly. As one veteran put it, “*What I like about the book, is the people in the book, how I relate to them or how they relate to me. ...The closest one I got to that related to me was the female that was in there, that was about my age. Her story kind of fell in line with mine.*” (ID4) Another said, “*I liked a lot of them stories you had in that booklet. That was good. A lot of stories from people in the armed service, they would tell you about things they had, explaining what they went through. So I was inspired by that.*” (ID7)

The sense of shared cultural experience with the veterans in the booklet was notable.

*“One of them, I think it was the Navy fellow...I kind of related to him because he was in the Navy and we went through the same thing*



*basically, and more or less have a different outlook on things than most people, because you have to be...open-minded to be in the Navy. You have to be willing to accept different customs, as well, and get along with them.” (ID8)*

One veteran suggested that we add more stories to the booklet, “*Maybe you could put in a little more of the interviews with vets. Because us veterans do like to hear what other veterans have to say.*” (ID10)

**Assessments of the booklet’s overall impact on planned engagement with providers varied.** There was a range of responses to interview questions centering on the booklet’s impact on planned behavior. One veteran (ID6) said he would not have done anything differently if he had seen the booklet before his last medical appointment, because he always asks for what he wants; this veteran had earlier related that he asked his provider for LCS and his cardiologist for a pacemaker. Another veteran, anticipating meeting a new provider, rested his decision to engage on whether the provider would reciprocate: “*I don’t know. We’ll have to see what kind of personality he has, I guess. Then I’ll go from there...If it’s a one-sided conversation, I don’t know.*” (ID4) A third veteran, however, was certain that the booklet had motivated her to participate in the clinical conversation.

*“Yes, it did. It really did. It gives me more empowerment...With this new doctor that I have, I felt like I had to listen instead of talk. But I realize that doctors, they can’t do anything to you if you don’t tell them. They can’t help you if they don’t know what’s going on, or if you’re skipping details. The book made me know that I have to tell them the whole truth and nothing but the truth.” (ID10)*

## Discussion

Experiences of the Black veterans we interviewed reinforce what both the literature and current events have made painfully clear: the desperate need for tools to empower Black patients, decrease disparities, and improve equity in healthcare. This work promotes positive attitudinal change among Black veterans who are often fighting an uphill battle to be heard in a clinical encounter<sup>30,31</sup> and who have been discouraged by prior racist healthcare experiences.<sup>6,7</sup> Using social norms theory, we developed a series of culturally tailored veteran narratives that counter typical expectations of a *normal* veteran’s engagement in patient-provider communication. Studies suggest that activating patients can disrupt racial bias that contributes to worse communication and care provided to Black patients.<sup>32</sup>

With the “You Are the Key” booklet, veterans are given permission by their peers to *rock the boat* – risk upsetting the clinician by expressing themselves - when their concerns are not acknowledged. This message appeared to resonate among the veterans we interviewed. The

veterans, all of whom were eligible for LCS, also appreciated the didactic information about SDM and LCS. The booklet could easily be adapted to other medical contexts, such as diabetes and heart disease, chronic illnesses that are well established as disproportionately affecting the Black population.<sup>33,34</sup>

The booklet was co-designed by a diverse group of veterans, and their expertise by experience is clearly reflected in the final product. Moreover, the same collaborative approach to care that is at the heart of SDM (clinicians are experts in medical science and patients are experts in their own experience) is also the foundation of PAR. By engaging veterans in co-design, we viewed them – and they viewed themselves – as partners in their care. Just as SDM builds trust in the patient-provider relationship, creating this space to collaborate on the research team can help build trust among veterans – in the research process and in VA health services.<sup>35</sup>

## Limitations

Our sample for qualitative interviews was limited and may not be generalizable, especially outside the veteran population. We interviewed veterans after they read the booklet; messages from the booklet may have influenced their responses, e.g., their perceptions of their current role in interactions with providers. It remains unclear to what extent the booklet directly impacts veteran behavior in clinical encounters. Regardless of the extent of the booklet’s impact, it is just one tool to improve empowerment among Black veterans in healthcare situations. It cannot replace the need for provider interventions (e.g., implicit bias training) or larger organizational changes to end systemic racism.

## Conclusion

To encourage SDM for LCS, we considered the context of the clinical encounter where SDM is meant to take place. We concluded that a broader approach, normalizing participation in clinical encounters, is required. The co-design team created the “You Are the Key” booklet to empower veterans, especially Black veterans, to *rock the boat* – whether regarding LCS or any other matter. The experiences of the Black veterans we interviewed reinforced that this is a systemic problem that extends beyond health communication. Yet their positive reactions to the booklet’s message of empowerment support the role that such tools can play in reducing disparities in patient-provider communication.

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