



Black US military veterans respond favourably to a booklet using narratives to normalise shared decision-making

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ABSTRACT

Background: Black Americans, including military veterans, experience worse health outcomes. In the United States, Black men have the highest lung cancer mortality and are less likely to undergo lung cancer screening (LCS). Mistrust caused by systemic racism can inhibit their participation in clinical conversations like shared decision-making (SDM). We sought to empower Black veterans to participate in SDM for LCS by normalising patients advocating for what matters most to them in clinical care decisions. We evaluated the impact of a booklet co-designed with veterans that includes four veteran narratives. They describe how each veteran began to trust their providers and engage in clinical conversations like SDM for LCS.

Study design: Pre-post intervention pilot study using surveys to evaluate the impact of the booklet and reactions to the narratives.

Methods: The survey was mailed to a random national sample of 450 Black veterans eligible for LCS but not yet screened. Respondents to the baseline survey were mailed the booklet and a follow-up survey.

Results: Thirty-nine veterans completed baseline and follow-up surveys. Mean agreement was above 3.0 (on a Likert scale of 1–5) for five statements about the booklet, with “Veterans eligible for screening should read” being the highest (mean 4.3). Information about LCS was rated most engaging (mean 3.2 on a scale of 1–4) and informative (3.3). The mean rating for veteran stories was 3.1 (engaging) and 2.9 (informative). Reactions to the narratives varied, including whether characters were relatable, likable, or influential. One narrative, describing a veteran slowly developing a trusting relationship with his provider, was particularly influential in encouraging respondents to talk with their doctor.

Conclusions: The positive reaction to the booklet supports the need to raise LCS awareness among LCS-eligible populations, and suggests that narratives may be a promising tool to increase engagement in care among Black veterans.

1. Introduction

It is well documented that Black Americans experience worse health outcomes compared to white Americans [1,2]. This disparity is reflected in the United States military veteran population; a 2021 analysis reported that Black veterans have worse self-rated health [3]. Implicit bias among healthcare professionals contributes to this disparity [4,5], as does institutional racism [6,7]. Moreover, historical acts of

discriminatory transgression [8] have created a legacy of mistrust in healthcare [9], and Black veterans continue to experience racism in healthcare encounters that may encourage disengagement [10].

Barriers including racism, implicit bias, and mistrust can inhibit Black patient participation in clinical conversations [11,12] and shared decision-making (SDM) [13] with providers. In SDM, patients and providers share information and deliberate together before making medical decisions [14]. Patient decision aids and other SDM supports can

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encourage involvement in decision-making [15], and show potential to reduce disparities and meet patients' informational needs [16]. Yet this potential may be unrealized without tailoring the intervention to the needs of the population [17].

Lung cancer screening (LCS) is one example of a health behaviour where mistrust can prevent Black veteran adherence to guideline-recommended care [18]. Lung cancer is the leading cause of cancer death among military veterans, and Black men have the highest lung cancer mortality in the US. LCS can decrease lung cancer deaths by 20 % [19], with greater benefit among Black participants [20], but LCS uptake is low among Black Americans [21,22]. However, LCS also exposes participants to potential harms (e.g., radiation exposure, emotional distress, complications from biopsies). SDM is called for in this situation where trade-offs should be discussed in the context of patient values [23]. While SDM has been found to reduce disparities in LCS [17], it rarely happens [24,25].

In our prior work, we sought to empower Black veterans to participate in clinical encounters, with a focus on SDM for LCS, by normalising patients advocating for what matters most to them in clinical care decisions. We co-designed with veterans a patient-facing booklet entitled "You Are the Key" to emphasize patients' central role in clinical conversations. The booklet includes four narratives (or stories) that describe veterans developing trust in their providers and engaging in clinical conversations such as SDM for LCS. Narratives involve a message of causality and a process of sensemaking by the audience; as they become engaged in the story, the audience finds themselves transported and identifying with the storytellers [26]. Once engaged, they may be more accepting of the information presented [27]. Black Americans respond favourably to stories about health [28–30], at least in part due to the strong background of using stories in African-American culture [31]. Recent research also suggests that storytelling may reduce stigma [32].

In qualitative interviews with Black veterans who had read the booklet, we learned that the veteran narratives resonated and contributed to a shared sense of military cultural experience. The co-design process and qualitative research results are described elsewhere [51]. Here we describe the results from a survey of Black veterans who received the booklet intervention. We focus on participant reactions to the booklet and its components, with emphasis on the veteran narratives.

2. Methods

Setting. The Veterans Health Administration (VA) is the largest nationally integrated healthcare system in the US, with over 150 medical centres and over 1000 community-based outpatient clinics. It provides care for 9 million US military veterans annually. Our Institutional Review Board designated this project, conducted in collaboration with VA's Office of Health Equity, as a quality improvement activity.

Study Design. In this pre-post intervention pilot study, we used surveys to evaluate the impact of an informational booklet mailed to participants. Participants were asked at follow-up (post) for their assessment of the booklet intervention and their reactions to booklet components.

Intervention. In our prior work, we involved veterans from diverse backgrounds in co-design of the intervention to ensure that the booklet was culturally appropriate and reflected the unique experience of US military veterans. We created "You Are the Key," a 30-page illustrated booklet for veterans that is available in print and online. The booklet includes: an author introduction; "You Are the Key," comparing conversations between an active patient and one who hesitates to participate in the conversation; "Reflect: Take a Quiz," which encourages readers to consider their own feelings and behaviour at medical appointments; "Reflect: Write Down Your Thoughts"; a "Doctor's Story" describing one provider's positive feelings towards talking with patients; frequently asked questions; tips on managing anxiety at a medical appointment; puzzles (crossword, word search); explanations of SDM

and LCS; LCS decision aid; and four one-page veteran narratives. Each narrative includes a message related to SDM for LCS. They are briefly described in conjunction with the study results, below, and are available in [Appendix A](#).

Survey instrument. We created baseline ("pre") and follow-up ("post") surveys to evaluate the impact of the booklet (See [Appendix A](#)). Two veterans who were unfamiliar with our study pretested the survey. They completed the survey and debriefed with a research team member to provide feedback on each section of the survey. As a result, we shortened the survey by removing overlapping measures and made formatting improvements.

The baseline survey collected demographic information and included validated measures of the respondent's engagement in care [33], communication and decision-making preferences, [34–36] perceived normative pressure for sharing preferences, [36] and LCS knowledge.

The post-intervention survey included detailed questions about the booklet plus the same measures asked at baseline. Respondents were asked their opinion about the length of the booklet and were given a text box for describing what "stood out" for them about the booklet. They were asked to respond to a series of statements about the booklet – on a Likert scale from 1 (strongly disagree) to 5 (strongly agree) – including: "It contained information that is useful to me;" "I will think about the information from the booklet at my next VA clinical appointment;" "I am more likely to talk with my VA healthcare provider now that I have read it;" "It made getting lung cancer screening a higher priority for me;" and "Veterans who are eligible for lung cancer screening should read this booklet."

The survey also asked how engaging and informative each section of the booklet was. Respondents were asked, "Looking back over the different sections of the booklet, how engaging did you find each section? (How much did they hold your attention, how much did you enjoy reading them?)," with response options on a scale from 1 (not at all engaging) to 4 (very engaging). Similarly, respondents were asked, "And looking back over the same sections of the booklet, how informative did you find each section? (How much did you learn something from them, how much did they introduce you to a new idea?)."

Regarding the narratives, survey respondents were instructed to "check the box for each statement that you feel is true for that veteran's story." Statements began "This veteran ..." with the following statement conclusions: "... is like me"; "... was hard for me to relate to"; "... could be a friend of mine"; "... was not very likable"; "... encouraged me to talk with my doctor"; "... made me think about my own conversations with my doctor"; and "... made me feel like I'm not alone." In the same survey item, respondents were also offered the following conclusions to the statement beginning "This veteran ...": "... encouraged me to talk with my doctor"; and "... made me think about my own conversations with my doctor."

Participant recruitment. The survey was administered July 2022–July 2023 to a random national sample of Black US military veterans who met US Preventive Services Task Force criteria for LCS – ages 50–80 years, currently smoking or quit within the past 15 years, and at least 20 pack-years total – but had not yet been screened. Participants were identified from the VA's national clinical data, which indicates eligibility for LCS but does not include criteria details. From that cohort, a total of 450 participants were randomly selected to receive baseline surveys by mail. We received a lower response rate than anticipated from the initial survey mailing ($n = 200$), and therefore completed additional baseline survey mailings ($n = 250$) as illustrated in [Fig. 1](#). Participants were given the option to opt out of further contact about the study. Participants who returned the baseline survey and did not opt out were sent a copy of the booklet and a follow-up survey, with instructions to complete and return it after reviewing the booklet. A \$5 gift card was included for completing the baseline survey; and a second \$5 gift card was mailed to the respondent upon receipt of the follow-up survey.

Analysis. Analyses were performed in SAS, version 9.4 (SAS Institute

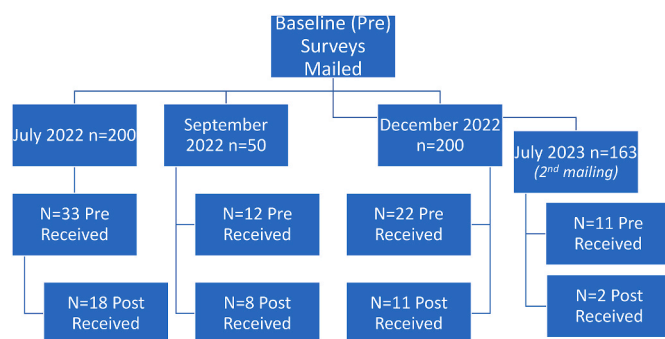


Fig. 1. Survey cohort diagram.

Inc., Cary, NC). We focus in this paper on descriptive analyses of items assessing the veterans' reactions to the booklet. Results are summarized as mean ratings on Likert scales. Missing responses were not included in calculating percentages or mean ratings.

3. Results

From the baseline survey mailing of $n = 450$, $n = 78$ baseline surveys were received (17 % response rate) and $n = 39$ paired follow-up surveys were received (50 % of baseline) (See Fig. 1.). Participant self-reported demographics are presented in Table 1.

Reactions to Booklet. Mean agreement was above 3.0 ("neither agree nor disagree") for the five statements about the booklet. Strongest mean agreement (4.3) was with the statement that "Veterans eligible for screening should read" the booklet. Respondents agreed that the booklet would make them more likely to talk with their healthcare provider (mean 4.05), made screening a higher priority (4.02), contained useful information (3.94), and that they will think about the information at their next VA appointment (4.02) (See Fig. 2.). Among respondents

rating the length of the booklet ($n = 31$), 87 % ($n = 27$) reported the booklet to be "just about the right length" and 13 % ($n = 4$) found the booklet to be too long; no respondents found it too short.

Booklet Components. The range in mean ratings for the booklet components in terms of being engaging and informative was 2.7–3.2 (on a scale of 1–4). The LCS facts were rated both most engaging (mean 3.2) and most informative (mean 3.3). Least engaging (mean 2.7) were both reflection components and the puzzles. Least informative (mean 2.7) was the "Take a Quiz" reflection component. Veteran stories received a mean rating for engagement of 3.1 and a mean rating for being informative of 2.9. Results are displayed in Table 2.

Veteran Narratives. Brief descriptions and a summary of survey results for each veteran narrative appear below. Numerical results indicate the number of respondents who reported feeling the statement was true for that veteran's story. Results are displayed in Fig. 3. See Appendix A for full narratives.

Robert – "I get what I need from my doctor." Robert says about himself, "I'm really active in my healthcare. That's worked for me ... No one's going to take care of me, but me." He also explains the need to build a relationship with VA healthcare providers, stating, "I built that relationship by being myself – not afraid to speak up, but also making people laugh." Notably, in survey responses, Robert was seen as "not very likable" (7 responses) compared to the other veteran narratives (1–3 responses), yet respondents also reacted to him as "like me" (15 responses), "could be a friend" (11 responses) and "made me feel like I'm not alone" (9 responses).

James – "I finally allowed the doctor to know who I am." James has experienced stigma from his history of cigarette smoking. He limited his medical appointments to avoid getting lectured about smoking. "... I was intimidated by the doctor. He knew everything, at least it seemed like that, and I assumed he was judging me for smoking and for not wanting to quit. I really didn't need to hear it from him." James describes slowly developing a trusting relationship with his provider and learning that "... he knew I couldn't quit smoking until I got a handle on my mental health." While more respondents indicated that James was hard to relate to (6 responses), compared to Robert (3 responses), James made more respondents "feel like I'm not alone" (14 responses) and his story was more influential in terms of engagement in care ("made me think about my own conversations with my doctor," 12 responses, and "encouraged me to talk with my doctor," 15 responses).

Maria – "I believe in myself. That makes the doctor believe in me." Maria explains the role of VA's Whole Health approach to care in motivating her to set life goals and engage in care to reach her goals. "I know when I go to my doctor, through what I've learned in Whole Health, that my opinion of my health matters more than anybody's." Respondents did not react particularly strongly to Maria's story. Her narrative received 3 responses each for being hard to relate to and not very likable, 7 responses for "made me think about my own conversations with my doctor," 8 responses for being "like me," and 9 responses each for "could be a friend," "made me feel like I'm not alone," and "encouraged me to talk with my doctor."

Nicole – "I didn't like talking to doctors." Nicole describes demeaning encounters with healthcare providers that led her to disengage from interacting with them. "When I would raise a concern about my health, the doctor would dismiss it. After that happens so many times, you start to doubt yourself." With a friend's encouragement, Nicole researched LCS and asked targeted questions at her next medical appointment. "I left my appointment feeling satisfied, confident, and proud of myself." Nicole was the hardest to relate to (8 responses) and received the fewest responses for being "like me" (5 responses), but also received only 1 response for being not very likable. Responses were not particularly strong for "encouraged me to talk with my doctor" (9 responses) and "made me think about my own conversations with my doctor" (9 responses).

Table 1
Participant characteristics of veterans ($n = 39$).

Age (in years), Mean (SD)	67.9 (4.4)
Gender, n (%)	
Male	36 (92.3)
Female	3 (7.7)
Health Status, n (%)	
Excellent	1 (2.6)
Very good	6 (15.4)
Good	15 (38.5)
Fair	16 (41.0)
Poor	1 (2.6)
Smoking Status, n (% of $n=38$) ^a	
Currently smoking	18 (47.4)
Not currently smoking	20 (52.6)
Marital Status, n (% of $n=36$) ^a	
Married	10 (27.8)
Unmarried	26 (72.2)
Housing, n (%)	
Self/family/friend	37 (94.9)
Other	2 (5.1)
Work Status, n (%) ^b	
Employed	6 (15.3)
Unemployed (Disability)	16 (41.0)
Unemployed	7 (17.9)
Retired	23 (59.0)
Education, n (% of $n=36$) ^a	
Some HS	1 (2.8)
HS grad or GED	12 (33.3)
College/beyond	23 (63.9)
Veteran Combat Status ($n=36$) ^a	
No	22 (61)
Yes	14 (39)

^a Missing responses.

^b Respondents may check more than one category.

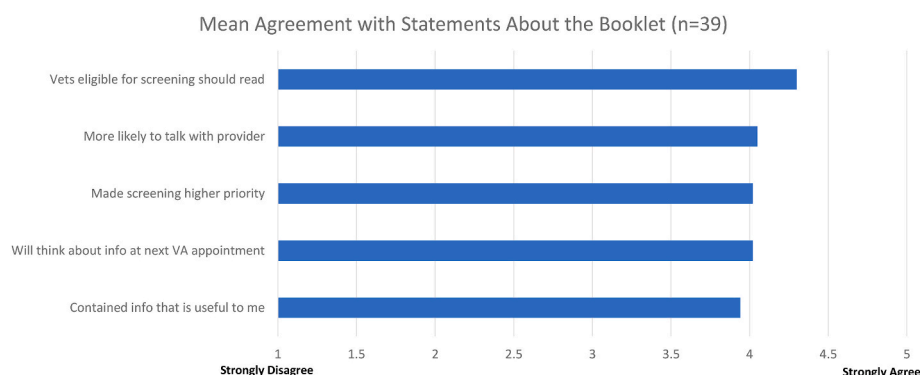


Fig. 2. Black Veterans agreed the booklet was useful and would influence their future behaviour.

Table 2
Mean Rating: “How engaging and informative were the booklet components?”

Section	Engaging (Range: 1–4)	Informative (Range: 1–4)
From the Authors (page 3)	2.8	2.9
You Are the Key (pages 4–5)	3.1	3.1
Veteran Stories (pp. 6, 19, 22, 25)	3.1	2.9
Reflect: Take a Quiz (p. 7)	2.7	2.7
Shared Decision-Making (p. 8)	3.0	3.1
Lung Cancer Screening (pp. 9–11)	3.2	3.3
Doctor's Story (p. 12)	2.8	2.9
Decision Aid (p. 13)	3.1	3.0
Frequently Asked Questions (p. 14)	2.9	2.9
Managing Anxiety (pp. 16–18)	3.1	3.0
Reflect: Write Down Your Thoughts (pp. 20–21)	2.7	2.8
Puzzles (pp. 23, 27)	2.7	2.8

4. Discussion

Our 30-page “You Are the Key” booklet includes a variety of components intended to engage readers. The didactic information about LCS proved to be most informative and engaging for our respondents, perhaps highlighting the primary need to raise awareness about LCS [37]. Other components of the booklet were found to be engaging and informative, however, and in combination may have contributed to

overall readability. Future research might include a comparison of the full booklet with the LCS didactic information alone. We emphasized analysis of the veteran stories in this evaluation due to the potential for narratives to increase engagement and therefore acceptance of the material.

The booklet stories, written by and about veterans, resonated with Black veterans. Respondents to our survey reported that the narratives encouraged them to talk with their doctor and made them think about conversations with their doctor. This finding is consistent with similar interventions using stories to influence health behaviour among minority populations [38], including to encourage participation in SDM [39]. It is also consistent with our earlier qualitative assessment of the booklet: Black veterans we interviewed highlighted the veteran stories, “the people in the book,” and their sense of shared military cultural experience with the characters [51].

To the extent that respondents found the veterans in the narratives to be “like me” or “could be a friend,” the veteran storytellers served as peers. The use of peers among veterans has been found to build trust in the healthcare system [40]; several studies have reported successful use of peers among the Black veteran population to enhance engagement in care [41,42]. Building on the positive reception to the booklet, our team is examining involving a peer who shares the principles introduced in the booklet in a community-based group education session, followed by one-on-one peer support, to raise LCS awareness and encourage participation in SDM.

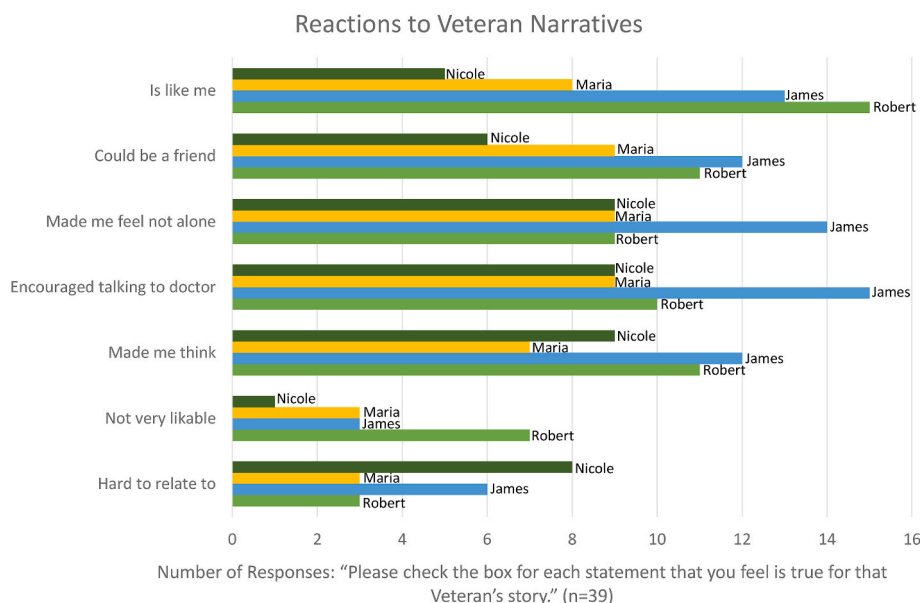


Fig. 3. Robert was very relatable, but James’s story was the most influential.

Our analysis compared reactions to the booklet's four narratives, which revealed key differences in aspects of both relatability and influence. It would be worth exploring particular characteristics of the narratives that readers might find more or less appealing. Future research on a larger scale could also map reactions to specific narratives with intentions to change specific health behaviours, to better understand which factors are most influential.

One limitation of our study is the imbalance between male (92 %) and female (8 %) respondents. While these participant characteristics reflect the demographics of US veterans in the age range eligible for LCS, our small number of women veteran participants is insufficient to capture the views of this important group. The intersectionality between being a veteran, Black, and female means that this population will have unique life [43] and healthcare [44] experiences. Therefore, different narratives may resonate with female veterans regardless of (or in addition to) their racial demographics – a question that deserves further exploration.

We had difficulty engaging Black veterans from our sample to participate in the survey, resulting in a low response rate that introduces the possibility of respondent bias. Mistrust in research among Black Americans [45,46] may have contributed to our low response rates, although it is not always clear that it is associated with decreased study participation among Black veterans [47]. Rather than pathologizing mistrust [48] among Black veterans (concluding that there is something inherent about Black veterans that leads to their lack of trust) we recognize the need to improve health research *trustworthiness* and counter the root cause of this mistrust [49]. Interventions that improve trustworthiness of an institution involve collaborating with community members and organizations – listening to them and centring their needs – in contribution to policy change [50]. Our study team's VA research centre, for example, developed a forum, the CHOIR-Community Collaborative to Advance Research Equity (C2CARE), where Black veterans determine a prioritised research agenda and partner with CHOIR investigators to advance that agenda.

Our pilot evaluation showed that a booklet co-designed by veterans and using narratives to normalise the conversation between providers and Black veteran patients can inform and engage readers and potentially influence their health behaviour. The positive reaction to the booklet from the Black veterans who took our survey indicates that the use of narratives shows promise as a tool for increased engagement in care among this marginalized population.

What this study adds

- Narratives describing veterans overcoming barriers to shared decision-making (SDM) can encourage Black veterans to talk with their doctor.
- Narratives may contribute to Black veteran-facing materials being seen as engaging and useful to the reader.
- Favourable reaction to the co-designed booklet is associated with a higher prioritisation of lung cancer screening among respondents.

Implications for policy and practice

- The findings from this pilot evaluation indicate that patient narratives may be a useful tool for increasing engagement in care among populations that experience mistrust as a barrier to patient-centered clinical interactions.

Data statement

A de-identified dataset that complies with guidance from the US Department of Veterans Affairs Office of Research & Development will be shared upon written request and only after executing a formal agreement that the recipient must safeguard the data and not make any

attempt to de-identify it.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.puhip.2025.100606>.

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