



HHS Public Access

Author manuscript

CHEST Pulm. Author manuscript; available in PMC 2024 October 10.

Published in final edited form as:

CHEST Pulm. 2024 September ; 2(3): . doi:10.1016/j.chpulm.2024.100044.

Adaptation of a Tailored Lung Cancer Screening Decision Aid for People With HIV

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Abstract

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Financial/Nonfinancial Disclosures

The authors have reported to *CHEST Pulmonary* the following: M. T. reports unrelated consultation fees from G02 Foundation. None declared (M. C. B., M. S., J. Z. B., N. M., N. G., P. E. R., B. J. W., T. C., K. C.).

Role of sponsors:

The funders had no role in the development of the research or the manuscript preparation.

Disclaimer: The views reflected in this manuscript do not reflect those of the United States government or the US Department of Veterans Affairs.

Additional information: The e-Appendixes are available online under “Supplementary Data.”

BACKGROUND: People with HIV are both at elevated risk of lung cancer and at high risk of multimorbidity, which makes shared decision-making (SDM) for lung cancer screening (LCS) in people with HIV complex. Currently no known tools have been adapted for SDM in people with HIV.

RESEARCH QUESTION: Can an SDM decision aid be adapted to include HIV-specific measures with input from both people with HIV and their providers?

STUDY DESIGN AND METHODS: This study used qualitative methods including focus groups of people with HIV and interviews with HIV care providers to adapt and iterate an SDM tool for people with HIV. Eligible participants were those with HIV enrolled in an HIV primary care clinic who met age and smoking eligibility criteria for LCS and HIV care providers at the clinic. Both the focus groups and interviews included semistructured discussions of SDM and decision aid elements for people with HIV. We used a framework-guided thematic analysis, mapping themes onto the Health Equity Implementation framework.

RESULTS: Forty-three people with HIV participated in eight focus groups; 10 providers were interviewed. Key themes from patients included broad interest in adapting LCS SDM specifically for people with HIV, a preference for clear LCS recommendations, and the need for positive framing emphasizing survival. Providers were enthusiastic about personalized LCS risk assessments and point-of-care tools. Both patients and providers gave mixed views on the usefulness of HIV-specific risk measures in patient-facing tools. Themes were used to adapt a personalized and flexible SDM tool for LCS in people with HIV.

INTERPRETATION: People with HIV and providers were enthusiastic about specific tools for SDM that are personalized and tailored for people with HIV, that make recommendations, and that inform LCS decision-making. Divergent views on presenting patient-facing quantitative risk assessments suggests that these elements could be optional but available for review. This tool may have usefulness in complex decision-making for LCS in this population and currently is being evaluated in a pilot prospective trial.

Keywords

early detection of cancer; health care disparities; health services accessibility; HIV; HIV infections; lung neoplasms; lung neoplasm diagnosis; qualitative research

Lung cancer is the leading cause of cancer death among people with HIV in the United States.¹ People with HIV are at higher risk of lung cancer than the general population because of both HIV-related factors and the risk associated with higher tobacco use in this population.^{2,3} The median age of people with HIV in the United States now is > 50 years, and with this so-called graying of the population, increased attention on lung cancer prevention and early detection is needed. Lung cancer screening (LCS) with annual low-dose chest CT imaging has been shown to reduce lung cancer mortality in individuals with high-risk tobacco use and now is endorsed widely for eligible people.^{4,5} Although few people with HIV were included in LCS trials,⁴ a large modeling study using similar methodology that guided US Preventive Services Task Force (USPSTF) LCS recommendations demonstrated that screening likely is similarly effective in those with well-controlled HIV.⁶

Guidelines recommend that LCS be performed only after shared decision-making (SDM), a process in which patients and clinicians share evidence and explore preferences and options to make a well-informed decision.^{7,8} However, no guidelines or tools are available to guide SDM in people with HIV. Personalized data best inform SDM processes to identify individuals who will derive the most benefit and least harm from screening. Concerns about heterogeneity in the risk to benefit ratio across the people with HIV eligible for LCS are particularly salient. People with HIV have higher smoking rates, a higher risk of lung cancer at younger ages, and a higher risk of lung cancer independent of smoking, so many likely can expect a favorable benefit to harm ratio.^{9,10} However, other aging people with HIV may have a complex burden of multimorbidity and may have a less favorable benefit to harm ratio and limited potential gains in life expectancy.^{11–14} Furthermore, although the literature is limited, current studies suggest low uptake of LCS among people with HIV and lower adherence to follow-up than the general population, and tailored efforts may be needed to improve LCS implementation in this population.^{15,16}

We recently assessed attitudes, barriers, and facilitators to LCS among people with HIV and their providers and found that people with HIV face both usual barriers to LCS care as well as barriers related to social determinants of health, but that an emphasis on HIV-related survivorship may be a facilitator to preventive care uptake.¹⁷ In this study, we sought input from LCS-eligible people with HIV and HIV care providers to adapt and tailor existing SDM tools to support a personalized LCS SDM approach.

Study Design and Methods

Study Setting and Overview

We used sequential qualitative methods—first focus groups with patients and then interviews with providers—to inform our adaptation of publicly available tools to guide SDM in people with HIV. People with HIV and providers eligible for this study either received or provided care at Madison Clinic at the University of Washington, the largest HIV primary care clinic in the Pacific Northwest of the United States. Eligible participants were people with HIV who were established in care with a Madison Clinic provider and met age and smoking eligibility criteria for LCS based on USPSTF 2021 guidelines: age 50 to 80 years, a smoking history equivalent to at least 20 pack-years, and smoking within the last 15 years. Eligible providers were those who maintained an HIV care practice at Madison Clinic. Patients were recruited from a voluntary clinic-maintained research registry, which represents 58% of all clinic patients. From this registry, 240 participants were contacted, 100 participants completed a telephone survey to determine eligibility, 75 participants were eligible, and 43 participants agreed to participate in the study. Providers were recruited via clinic listserv with the first 10 respondents enrolled. Study recruitment details were published previously.¹⁷ This study was approved by the Fred Hutchinson Cancer Center Institutional Review Board (Identifier, IR10557), and all participants provided written informed consent.

Measures

Both patient and provider participants completed brief demographic surveys before qualitative discussions. Focus groups and interviews were semistructured following

qualitative guides developed by six coauthors (M. T., M. C. B., M. S., J. Z. B., B. J. W., and K. C.) with broad experience in HIV care, implementation science, and LCS. Guides were developed with attention to the Tailored Implementation of Chronic Diseases checklist and the Consolidated Framework of Implementation Research (e-Appendixes 1 and 2).^{18,19} We used the Health Equity Implementation Framework to guide the analysis and iterations of the tailored SDM tool.²⁰

The initial half of the qualitative discussions focused on broad determinants of LCS care, with key results reported in a prior article.¹⁷ In the second half, patients and providers reviewed SDM tools and approaches. First, we conducted eight focus groups with two to eight patients between February and April 2021. Focus groups were conducted remotely via Health Insurance Portability and Accountability Act-compliant Zoom, with one in-person option. Each focus group lasted between 1 and 1.5 h. Participants interacted with the www.shouldiscreen.com decision aid with prompts around the Guideline Factors of the Tailored Implementation of Chronic Diseases checklist, including cultural appropriateness, accessibility, consistency, and compatibility of the decision aid. Facilitators asked participants about potential additions and changes to the decision aid, including personal assessments of lung cancer and competing risks and tailored approaches for people with HIV. After the focus groups were completed, the study team conducted the initial analysis of the transcripts to inform the content of the provider interview guide and to adapt a tailored SDM tool. Based on input from participants regarding preferences for screening recommendations, the DecisionPrecision tool (available at www.screenlc.com) was adapted to HIV-specific contexts for these discussions. All 10 provider interviews were conducted over Zoom between January and February 2022. These interviews lasted 45 min and focused on review and input on a draft SDM tool output with three diverse patient scenarios.

Focus group and interview recordings were transcribed and checked for accuracy by the study facilitators (M. C. B. and M. S.). Transcripts were analyzed using a constant comparison method of thematic analysis.²¹ The entire study team developed a set of a priori codes for analyses based on guide questions and mapped to the Health Equity Implementation Framework. For the focus groups, the three analysts (M. S., M. C. B., and P. E. R.) then coded an initial transcript separately and reviewed and iterated on the codebook together to ensure consistency. The remaining transcripts then were assigned randomly and double-coded. The study team checked in periodically to review progress, to discuss coding, and to update the codebook as needed. Coding of provider interviews followed the same process, except that in this instance, the three coders (M. T., M. S., and M. C. B.) coded each of the transcripts. The analytic teams reviewed coded segments for both focus groups and interviews to identify preliminary themes mapped onto Health Equity Implementation Framework domains. The entire study team then reviewed all themes and made final iterations to the SDM tool.

Results

Patient Focus Groups

A total of 43 people with HIV participated across eight focus groups. Participants were predominately male (81%) with a median age of 59 years (Table 1). Most had annual

incomes of < \$30,000 per year, and most (65%) reported chronic diseases other than HIV that required three or more provider visits per year. All the participants met USPSTF smoking eligibility for LCS, with 37% currently smoking and a median history of 35 pack-years of cigarette use.

Within the domain of innovation factors, participants largely were aware of the relevance of HIV in discussions of LCS: most acknowledged both increased smoking in people with HIV and the effect of HIV on other chronic health issues (Table 2). Yet, many participants were unaware of the independent association between HIV and lung cancer. Regardless, awareness of cancer risk, coupled with attitudes supporting HIV-tailored approaches, translated to high-level support from participants for the SDM process for LCS to be adapted for people with HIV.

We found diverging views when asked more specifically about different approaches to tailoring discussions about LCS for people with HIV. Some participants expressed that lung cancer risk primarily should consider smoking with less specific emphasis on HIV-related health, whereas others believed it appropriate to incorporate measures of HIV control and HIV-associated comorbidity in an SDM discussion. Those with well-controlled HIV infection often were less concerned with their HIV status and believed that their smoking history should be central. Regardless, all participants who commented thought that it was valuable to have a dedicated tool and approach to LCS.

Differences in opinions on how HIV-related health effects should be incorporated into LCS SDM also extended to attitudes toward incorporation of quantitative data. We found that participants were split on using a patient-facing tool that uses individualized data to inform quantitative risk assessments: some viewed incorporating HIV-adjusted data helpful, whereas others were wary of predictive analytic approaches, given previous experiences with inaccurate life expectancy prognostication at the start of the HIV epidemic. This second group of individuals preferred more general information adapted for people with HIV, such as framing LCS as a health-promoting activity supporting survivorship. Many participants also had difficulty interpreting risk over time, which also may have contributed to this attitude. Overall, many considered the availability of these measures to be “helpful,” but wanted their review to be “optional.”

Within the domain of the clinical encounter, most participants preferred to interact with these tools with a provider and reported that they both wanted and would accept their providers’ recommendations. However, some questioned why providers would not recommend screening if they were eligible. A few patients reported that they preferred to review data or come to their own conclusions about undergoing screening. Within recipient and context factors, a personal connection to cancer (either through themselves, friends, or family) informed participants’ attitudes and enthusiasm for screening. Their histories of chronic HIV management also informed their attitudes toward the SDM process: many emphasized the need for positive messaging linked with survivorship in a chronic disease context. Previous negative experiences with the health care system also led a few participants to express medical skepticism toward risk assessments and other LCS processes; these participants often wanted more supporting evidence.

Provider Interviews

We incorporated feedback from focus groups to develop the SDM tool further, which incorporated a personalized risk of lung cancer, risk of death from all causes, a personalized number needed to screen to prevent one lung cancer death assessment, and a pictogram depicting both benefits and harms of screening in a theoretical population of 1,000 patients similar to the index patient. The tool also provides an LCS recommendation on a spectrum of discourage screening, preference sensitive, and encourage screening based on eligibility, personal risk of lung cancer, and risk of all-cause mortality. Providers were led through three patient scenarios to gather feedback on scenarios with different outputs in the screening tool. Most provider participants were female, White, and attending physicians trained in infectious diseases (Table 3).

Within the domain of innovation factors, providers universally supported tailored tools and measures to inform LCS decision-making in people with HIV infection (Table 4). They particularly endorsed visual information tailored to a patient's risk and explicit screening recommendations. Providers acknowledged that multimorbidity posed a major challenge in SDM (or even discussing LCS with patients), but were mixed on whether quantitative measures would be useful to patients. Many expressed concerns that competing risks described as a "risk of dying from all causes" might not be well received. However, they believed that these quantitative measures of risk would help them, as providers, make LCS decisions. Providers also were mixed on whether they would discourage screening in a setting where a patient was eligible but unlikely to benefit because of competing risks.

Within other domains, connected themes emerged that emphasized provider-level barriers to engaging in SDM and strong support for a tool that could address these barriers. These barriers included limited time and resources and less awareness of LCS eligibility compared with other screenings. They supported the delivery of a tool integrated into the electronic health record (EHR) to improve efficiency.

SDM Tool

The final SDM tool integrated feedback from both patients and providers. It includes base elements from the DecisionPrecision LCS tool that both groups endorsed: an option for personalized risk assessment (using data from within a patient's EHR), a personalized screening recommendation, and easy-to-interpret visuals of screening benefits and harms. Based on feedback from the qualitative assessments, the tool was adapted to include a more interpretable five-risk assessment, including a modification for the risk of lung cancer using the Lung Cancer Risk Assessment Tool with a conservative modifier of 1.2 to capture lung cancer risk associated with HIV,²² a personalized number needed to screen, a personalized assessment of 5-year risk of death using the Veterans Aging Cohort Study index 2.0 to help inform screening recommendations, and a customizable level of data detail based on patient preferences.²³ The recommendations of encourage screening, discourage screening, or preference-sensitive screening are in accordance with USPSTF 2021 eligibility, but provide additional information based on personal risk assessment. Discourage screening is recommended for situations where patients do not meet USPSTF criteria or have a predicted 5-year risk of death of > 50%. Encourage screening is recommended for patients who meet

LCS criteria, have a 5-year risk of lung cancer of > 2%, and have a 5-year risk of death of < 50%. Preference sensitive is recommended for situations where patients meet LCS criteria, have a < 50% 5-year risk of death, but also have a < 2% risk of lung cancer in 5 years. An example of the final tool for a hypothetical patient is seen in Figure 1.

Discussion

This qualitative study used patient and provider feedback to adapt an SDM tool to meet the needs of people with HIV and their providers. We found broad enthusiasm among participants for HIV-specific approaches to LCS. Themes from patient interviews emphasized that approaches that provided personalized recommendations in SDM were highly valued. However, we found a diversity of preferences on level of detail for discussions of lung cancer risk and competing risks expressed as life expectancy and the emphasis placed on measures of HIV control and related health. Providers valued tools (1) with quantitative and personalized data, (2) that supplemented their own discussions and knowledge gaps, and (3) that were embedded efficiently within the EHR. Providers diverged in how much information they wanted to share with patients, particularly around mortality assessments, and how and whether they would use tools to discourage screening in those whose harms may outweigh the benefits. Our findings align with previous SDM literature that has found a similar divergence in how much data to share with patients, endorsing starting with personalized recommendations and general information, with the ability to opt in to much more detail if the patient desires to support patient autonomy.^{24,25} Our study extends on this work to provide insight into how providers might conduct SDM discussions in people with HIV and to introduce a flexible and personalized approach to point-of-care SDM for LCS in people with HIV through an adapted tool.

We found broad enthusiasm among most patients and all providers for a tailored approach to LCS in people with HIV, which both reflects the acknowledgment of high lung cancer risk among people with HIV and positive experiences with HIV-tailored care. A recent study using national-level data suggests that the cumulative incidence of lung cancer in people with HIV over 5 years is 1.36% (95% CI, 1.17%–1.53%),²⁶ making them, as a group, at extremely high risk of lung cancer. People with HIV are also at much higher risk of other comorbidities associated with aging than the general population. This raises concern that many patients may have a comorbidity profile that will lead to more harms than benefits of LCS.^{27,28} More than 50% of people with HIV infection in the United States now are older than 50 years, and population-based studies demonstrate a higher prevalence of common comorbidities in this group; further, multimorbidity (two or more chronic age-related conditions) affects 25% to 50% of all people with HIV in the United States.^{29–31} Most guidelines suggest incorporating multimorbidity into SDM, but evidence that this routinely occurs in either people with HIV or others is limited.³²

A tailored approach not only was endorsed by stakeholders, but also this approach is well matched to HIV care in the United States. Although a variety of HIV care models have been suggested, most people with HIV in the United States are cared for by HIV specialists.³³ Adapted primary care guidelines are well supported based on different risk profiles of people with HIV in the United States.³⁴ Particular enthusiasm exists for models that can be tailored

to provide people with specific risks associated with chronic HIV infection and such models currently available for cardiovascular disease.^{35,36}

Although broad support exists for an adapted approach to SDM for people with HIV, patients and providers expressed variable preferences toward how to incorporate this into SDM. Some patients endorsed an approach that included a review of detailed and personalized risk data, whereas others preferred not to interact with the data themselves and found quantitative risk estimates either challenging to interpret or unnecessary. Providers uniformly were in agreement that the data were helpful, but they had mixed opinions on whether they would share these numbers with patients. However, broad agreement was found among both groups that an SDM conversation should include messages such as: (1) HIV increases your risk of lung cancer, but both smoking history and age are more important risk factors, and (2) HIV control greatly reduces competing risk and enhances survival. The divergent findings around patient review of personalized risk data suggest that these should be largely provider facing in all instances to help inform and contextualize screening recommendations, but that patients should be allowed to opt in to data review. For these reasons, in the final version of the tool that is being evaluated prospectively, we are offering participants the option of reviewing either (1) only summary statements that reflect eligibility, risk of lung cancer, and general magnitude of competing risk or (2) numerical estimates including 5-year risk of lung cancer, number needed to screen, and 5-year mortality risk. Regardless of attitudes toward granular risk estimates, our results suggest that patients prefer messaging to be framed positively and to be linked to other decisions supporting survivorship for people with HIV. Although the emphasis of this work is on HIV, it is also important to remember that patients have other identities and experiences (such as prior experiences with cancer) that also inform their screening attitudes and that these should be incorporated into SDM.

This is the first study we are aware of to use patient and provider input to adapt an SDM tool for people with HIV, which is essential formative work to create tools that meet stakeholder needs before evaluation in a pragmatic trial. Adapting this tool also has revealed areas for future research. First, lung cancer risk estimations used for the tool were based on data from study cohorts (the National Lung Screening Trial) multiplied by a 1.2-fold increased risk associated with HIV based on limited studies. Future iterations would be informed best by more sophisticated lung cancer risk models (which need to be developed) based on data from people with HIV. Second, limited prospective data are available to inform personalized risk of harms, either in the general population or in people with HIV. Furthermore, as more clinical LCS data emerge, ongoing work is needed to elucidate fully the cut points between encouraging and discouraging recommendation thresholds. Finally, as emphasized by providers in this study, these tools need to become automated and integrated into EHRs.

The strengths of this study include the engagement of a multidisciplinary team, rigorous qualitative methods, and an analytic framework based in both implementation determinants and health equity. This is also one of the first studies to attempt to adapt LCS SDM tools for people with HIV, using direct input from people with HIV and their providers. A primary limitation of this work is that our patient and provider populations drew from one HIV clinic. Moreover, focus group participants all were actively engaged in care and were part of

a voluntary research registry of patients, so perspectives regarding LCS may differ among those with less established relationships and access to care.

Interpretation

In conclusion, we used sequential semistructured discussions with people with HIV and providers to adapt a publicly available SDM tool for the care of people with HIV. The tool emphasizes both personalized measures of lung cancer risk and competing risk and offers screening recommendations for people with HIV, but also allows for a variable level of detail and information. This tool can assist with point-of-care decision-making, engagement, and personalization in a patient population with potential high-net benefits, but also potential harms from screening.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Funding/Support

This project was supported by the National Cancer Institute, National Institutes of Health, through a supplemental grant to the Fred Hutchinson/University of Washington Cancer Center Support Grant (project leaders, M. T. and K. C.) [Grant P30 CA015704]. M. C. B. was supported by the National Heart, Lung, and Blood Institute [Postdoctoral Fellowship T32HL702842].

ABBREVIATIONS:

EHR	electronic health record
LCS	lung cancer screening
SDM	shared decision-making
USPSTF	US Preventive Services Task Force

References

1. Simard EP, Engels EA. Cancer as a cause of death among people with AIDS in the United States. *Clin Infect Dis.* 2010;51(8):957–962. [PubMed: 20825305]
2. Kirk GD, Merlo C, O’Driscoll P, et al. HIV infection is associated with an increased risk for lung cancer, independent of smoking. *Clin Infect Dis.* 2007;45(1):103–110. [PubMed: 17554710]
3. Robbins HA, Pfeiffer RM, Shiels MS, Li J, Hall HI, Engels EA. Excess cancers among HIV-infected people in the United States. *J Natl Cancer Institute.* 2015;107(4).
4. Aberle DR, Adams AM, Berg CD, et al. ; National Lung Screening Trial Research Team. Reduced lung-cancer mortality with low-dose computed tomographic screening. *N Engl J Med.* 2011;365(5):395–409. [PubMed: 21714641]
5. de Koning HJ, van der Aalst CM, de Jong PA, et al. Reduced lung-cancer mortality with volume CT screening in a randomized trial. *N Engl J Med.* 2020;382(6):503–513. [PubMed: 31995683]
6. Kong CY, Sigel K, Criss SD, et al. Benefits and harms of lung cancer screening in HIV-infected individuals with CD4+ cell count at least 500 cells/mul. *AIDS.* 2018;32(10):1333–1342. [PubMed: 29683843]

7. Moyer VA; United States Preventive Services Task Force. Screening for lung cancer: U.S. Preventive Services Task Force recommendation statement. *Ann Intern Med.* 2014;160(5):330–338. [PubMed: 24378917]
8. Elwyn G, Frosch D, Thomson R, et al. Shared decision making: a model for clinical practice. *J Gen Intern Med.* 2012;27(10):1361–1367. [PubMed: 22618581]
9. Winstone TA, Man SF, Hull M, Montaner JS, Sin DD. Epidemic of lung cancer in patients with HIV infection. *Chest.* 2013;143(2):305–314. [PubMed: 23381313]
10. Shiels MS, Pfeiffer RM, Engels EA. Age at cancer diagnosis among persons with AIDS in the United States. *Ann Intern Med.* 2010;153(7):452–460. [PubMed: 20921544]
11. Kong AM, Pozen A, Anastos K, Kelvin EA, Nash D. Non-HIV comorbid conditions and polypharmacy among people living with HIV age 65 or older compared with HIV-negative individuals age 65 or older in the United States: a retrospective claims-based analysis. *AIDS Patient Care STDS.* 2019;33(3):93–103. [PubMed: 30844304]
12. d'Arminio Monforte A, Diaz-Cuervo H, De Luca A, et al. Evolution of major non-HIV-related comorbidities in HIV-infected patients in the Italian Cohort of Individuals, Naive for Antiretrovirals (ICONA) Foundation Study cohort in the period 2004–2014. *HIV Med.* 2019;20(2):99–109. [PubMed: 30461158]
13. Pelchen-Matthews A, Ryom L, Borges AH, et al. Aging and the evolution of comorbidities among HIV-positive individuals in a European cohort. *AIDS.* 2018;32(16):2405–2416. [PubMed: 30134296]
14. Petoumenos K, Huang R, Hoy J, et al. Prevalence of self-reported comorbidities in HIV positive and HIV negative men who have sex with men over 55 years—the Australian Positive & Peers Longevity Evaluation Study (APPLES). *PLoS One.* 2017;12(9):e0184583. [PubMed: 28886173]
15. Islam JY, Yang S, Schabath M, et al. Lung cancer screening adherence among people living with and without HIV: an analysis of an integrated health system in Florida, United States (2012–2021). *Prev Med Rep.* 2023;35:102334. [PubMed: 37546581]
16. Lopez W, Sayles H, Bares SH, Fadul N. Low rates of lung cancer screening referrals in patients with human immunodeficiency virus: a correlational study. *Cancer Control.* 2022;29:10732748221103624.
17. Triplette M, Brown MC, Snidarich M, et al. Lung cancer screening in people with HIV: a mixed-methods study of patient and provider perspectives. *Am J Prev Med.* 2023;65(4):609–617.
18. Flottorp SA, Oxman AD, Krause J, et al. A checklist for identifying determinants of practice: a systematic review and synthesis of frameworks and taxonomies of factors that prevent or enable improvements in healthcare professional practice. *Implement Sci.* 2013;8:35. [PubMed: 23522377]
19. Damschroder LJ, Aron DC, Keith RE, Kirsh SR, Alexander JA, Lowery JC. Fostering implementation of health services research findings into practice: a consolidated framework for advancing implementation science. *Implement Sci.* 2009;4. 50–5908-5904–5950.
20. Woodward EN, Matthieu MM, Uchendu US, Rogal S, Kirchner JE. The health equity implementation framework: proposal and preliminary study of hepatitis C virus treatment. *Implement Sci.* 2019;14(1):26. [PubMed: 30866982]
21. Chapman AL, Hadfield M, Chapman CJ. Qualitative research in healthcare: an introduction to grounded theory using thematic analysis. *J R Coll Physicians Edinb.* 2015;45(3):201–205. [PubMed: 26517098]
22. Katki HA, Kovalchik SA, Berg CD, Cheung LC, Chaturvedi AK. Development and validation of risk models to select ever-smokers for CT lung cancer screening. *JAMA.* 2016;315(21):2300–2311. [PubMed: 27179989]
23. Tate JP, Sterne JAC, Justice AC. Albumin, white blood cell count, and body mass index improve discrimination of mortality in HIV-positive individuals. *AIDS.* 2019;33(5):903–912. [PubMed: 30649058]
24. Caverly TJ, Hayward RA. Dealing with the lack of time for detailed shared decision-making in primary care: everyday shared decision-making. *J Gen Intern Med.* 2020;35(10):3045–3049. [PubMed: 32779137]

25. Caverly TJ, Skurla SE, Robinson CH, Zikmund-Fisher BJ, Hayward RA. The need for brevity during shared decision making (SDM) for cancer screening: veterans' perspectives on an "everyday SDM" compromise. *MDM Policy Pract.* 2021;6(2):23814683211055120.
26. Haas CB, Engels EA, Horner MJ, et al. Trends and risk of lung cancer among people living with HIV in the USA: a population-based registry linkage study. *Lancet HIV.* 2022;9(10):e700–e708. [PubMed: 36179753]
27. Tanner NT, Dai L, Bade BC, Gebregziabher M, Silvestri GA. Assessing the generalizability of the national lung screening trial: comparison of patients with stage 1 disease. *Am J Respir Crit Care Med.* 2017;196(5):602–608. [PubMed: 28722466]
28. Gould MK, Munoz-Plaza CE, Hahn EE, Lee JS, Parry C, Shen E. Comorbidity profiles and their effect on treatment selection and survival among patients with lung cancer. *Ann Am Thorac Soc.* 2017;14(10):1571–1580. [PubMed: 28541748]
29. Wong C, Gange SJ, Moore RD, et al. Multimorbidity among persons living with human immunodeficiency virus in the United States. *Clin Infect Dis.* 2018;66(8):1230–1238. [PubMed: 29149237]
30. Maggi P, Santoro CR, Nofri M, et al. Clusterization of co-morbidities and multi-morbidities among persons living with HIV: a cross-sectional study. *BMC Infect Dis.* 2019;19(1):555. [PubMed: 31238916]
31. Smit M, Brinkman K, Geerlings S, et al. Future challenges for clinical care of an ageing population infected with HIV: a modelling study. *Lancet Infect Dis.* 2015;15(7):810–818. [PubMed: 26070969]
32. Rivera MP, Tanner NT, Silvestri GA, et al. Incorporating coexisting chronic illness into decisions about patient selection for lung cancer screening. An official American Thoracic Society research statement. *Am J Respir Crit Care Med.* 2018;198(2):e3–e13. [PubMed: 30004250]
33. Kimmel AD, Martin EG, Galadima H, et al. Clinical outcomes of HIV care delivery models in the US: a systematic review. *AIDS Care.* 2016;28(10): 1215–1222. [PubMed: 27177151]
34. Thompson MA, Horberg MA, Agwu AL, et al. Primary care guidance for persons with human immunodeficiency virus: 2020 update by the HIV Medicine Association of the Infectious Diseases Society of America. *Clin Infect Dis.* 2021;73(11):e3572–e3605. [PubMed: 33225349]
35. Yu J, Liu X, Zhu Z, et al. Prediction models for cardiovascular disease risk among people living with HIV: a systematic review and meta-analysis. *Front Cardiovasc Med.* 2023;10: 1138234.
36. McGettrick P, Mallon PWG, Sabin CA. Cardiovascular disease in HIV patients: recent advances in predicting and managing risk. *Expert Rev Anti Infect Ther.* 2020;18(7):677–688. [PubMed: 32306781]

Take-home Points

Study Question:

Can a shared decision-making (SDM) aid for lung cancer screening (LCS) be adapted to include HIV-specific measures with input from both people with HIV and their providers?

Results:

With input from sequential qualitative discussions with people with HIV and primary HIV care providers, we adapted a decision aid for SDM in people with HIV to include specific measures of risk, specific LCS recommendations, and HIV-specific framing.

Interpretation:

A specific tool for SDM for people with HIV was welcomed and may have usefulness in complex decision-making for LCS in this population.

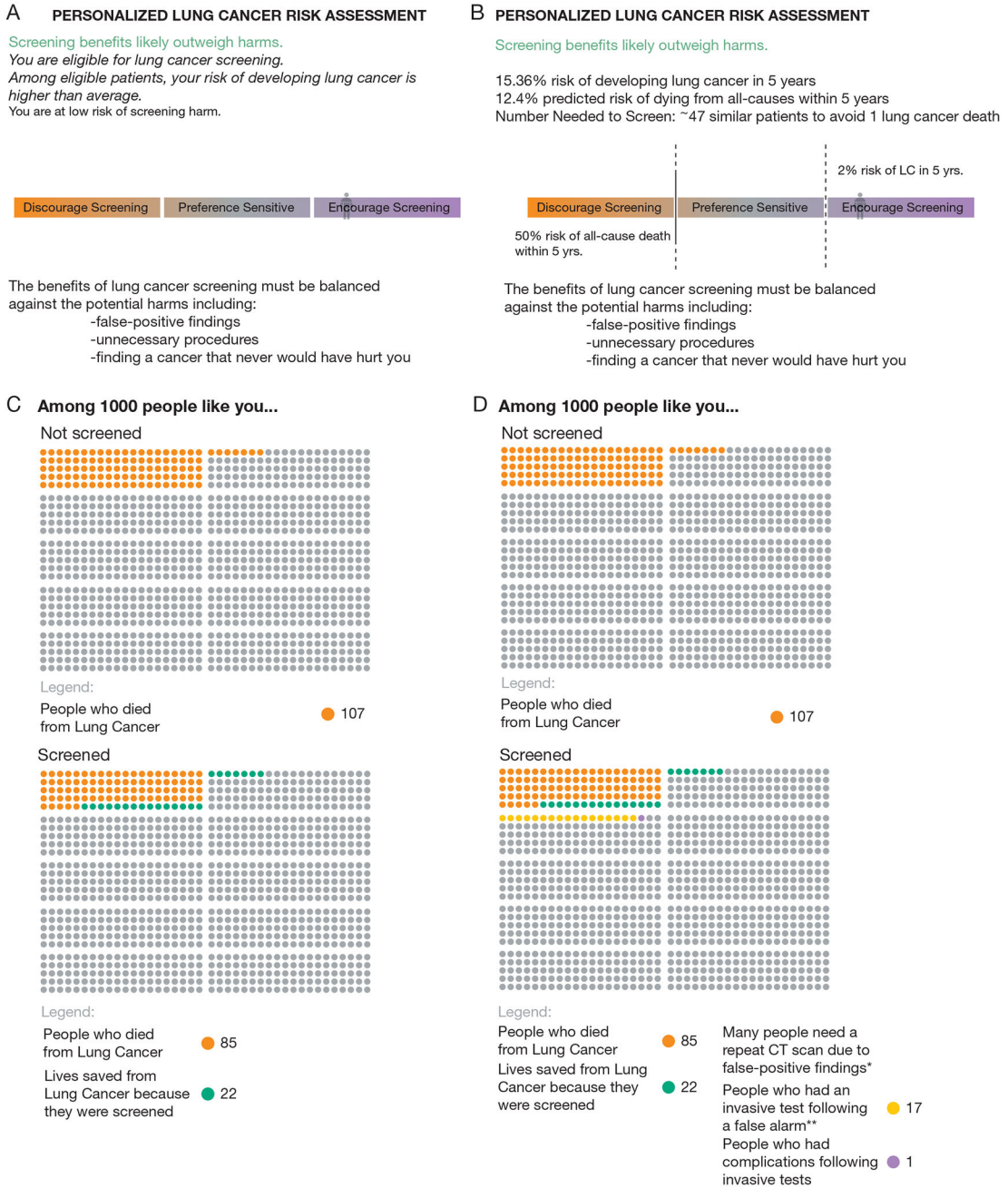


Figure 1 –
 Example of a tailored shared decision-making tool for a patient. The patient is a 68-year-old man with COPD, chronic kidney disease, and long-standing well-controlled HIV. He currently smokes and has a 50-pack-year history of smoking. A, Personalized risk assessment that does not include quantitative values, providing a summary recommendation for screening, confirming eligibility, and comparing risk with that of the average patient with lung cancer screening. B, Risk assessment data shown at a patient’s request, including a numeric 5-year risk of lung cancer developing, a 5-year risk of mortality, and a personalized number needed to screen in a group of similar patients. C, Pictogram allowing visualization

of the benefits of screening in lives saved from lung cancer in a hypothetical cohort of 1,000 people who are similar to the index patient. D, Pictogram including a depiction of significant harms of screening, including unnecessary invasive testing and complications.

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TABLE 1]

Patient Focus Group Participant Self-Reported Characteristics (N = 43)

Characteristic	No. (%)
Sex	
Female	7 (16)
Male	35 (81)
Nonbinary or other gender	1 (2)
Age	59 (53–67)
Race (> 1 response allowed)	
American Indian or Alaska Native	5 (12)
Asian	3 (7)
Black or African American	4 (9)
Native Hawaiian or other Pacific Islander	0
White	29 (67)
Other (self-reported as “mixed” race)	3 (7)
Other (self-reported as “human” race)	2 (3)
Hispanic ethnicity	3 (7)
Employment status	
Full-time	7 (16)
Part-time	11 (26)
Retired	7 (16)
Unemployed	3 (7)
Disabled	15 (35)
Education	
Less than high school graduate	6 (14)
High school graduate or GED	9 (21)
Some college	12 (28)
College graduate	9 (21)
Graduate degree	3 (7)
Annual household income, \$	
< 5,000	0
5,000–15,000	13 (30)
15,001–30,000	11 (26)
30,001–50,000	4 (9)
50,001–75,000	4 (9)
> 75,000	3 (7)
Prefer not to answer	3 (7)
Don’t know	5 (12)
Insurance status (> 1 response allowed)	
Private health insurance or HMO	14 (33)
Self-pay	0
Medicare	20 (47)

Characteristic	No. (%)
Medicaid	19 (44)
Charity care or other subsidized insurance	5 (12)
Other	1 (2)
Smoking status	
Currently smoking	16 (37)
Prior smoking (> 30 d since quit)	27 (63)
History of cigarette use, pack-y	35 (23–44)
Reported prior lung cancer screening	12 (28)
Reported any prior cancer screening	28 (65)
Reported chronic diseases other than HIV requiring > 3 provider visits/y	28 (65)

Data are presented as No. (%) or median (interquartile range). GED = General Educational Development; HMO = Health Maintenance Organization.

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Key Themes From Patient Focus Groups Organized by the Health Equity Implementation Framework

TABLE 2 |

Framework Domain	Theme	Representative Quotations
Innovation factors	<p>Participants' perceptions of their lung cancer risk is tied directly to their smoking history, with few acknowledging other factors including HIV status.</p> <p>Participants are generally supportive of resources and conversations around preventative care that consider HIV status, even if they are unaware of direct connections to lung cancer.</p> <p>Participants differed on whether they preferred to interact with a tool that incorporated personalized and detailed measures (such as risk of lung cancer or mortality) vs more general approaches to convey LCS recommendations.</p> <p>Patients have difficulty interpreting commonly used statistics in personalized tools (such as lung cancer risk), particularly risk over a finite period, which often led to a misunderstanding of risk.</p> <p>Most participants value receiving a provider-driven recommendation for lung cancer screening, but many also want more information, explanation, or to research independently to inform these decisions.</p>	<p>"I already know I'm in a high category of risk factors for lung cancer, having been a heavy heavy cigarette smoker and addict and now a vaper ... with that progressing to COPD. I think all those are pretty good indicators that I'm at—already at a high risk level."</p> <p>"Ok, yeah I said no, I don't think it is important [to include markers of HIV status in a tool]. I don't think it's important for many other aspects of my health, and I think my smoking and my exposure is more important than my HIV. I've been undetectable for many many years and I'm not concerned about that part of it."</p> <p>"With our immune system being compromised, and stuff, I think it's really important that we get checked for all kinds of different diseases, cancer is being one of them"</p> <p>"It might be useful for a couple of reasons, even if there's not a definitive link between HIV and lung cancer, and one is that it for the people that are getting screened, it can kind of tie their general health care that they're getting for HIV in their mind, to this additional procedure that might find something that we're not sure if it's related to HIV or not."</p> <p>"I also think, you know, if you could just make the different variables, like just check boxes or options that people could, you know, could check off in the tool, and then you know, they could play around with using different risk factors in determining you know, what their lifespan is ... I would love something like that."</p> <p>"I think if that had a section at the end where you could click on it and they would say we can refer this study to your caregiver ... and they can discuss with you effects on longevity and stuff like that. Because I think it's really something that needs a better interpretation than kind of just like a YouTube thing where it says how long are you going to live, you know."</p> <p>"Probably, probably it would help to know what 6% translates into in years lost or whatever. I think that would be better to shock me into taking it more seriously."</p> <p>"I don't know I guess somebody smoking for 32 years I would think that they would have a higher risk than 1%."</p>
Clinical encounter	<p>Personal history with lung cancer or other forms of cancer impacts perceived importance of screening.</p>	<p>"I gotta hear it from my doctor, and if they recommend that I don't have it, then I don't have it, if they recommend that I do then I will."</p> <p>"I want to be able to trust my doctor, to know if, when she should mention something to me and when she shouldn't and I appreciate that she does and so, I may choose otherwise because I don't let doctors tell me what to do when it comes to my health anymore, I did that when I first got sick, but that was years ago and I've learned my lesson from it."</p> <p>"I'm not saying I'd run around and get, keep getting opinions until somebody told me what I wanted to hear, but I just think it's good to ask questions and find out why."</p> <p>"Well that it's good. Cancer runs in my family, so I was having a mammogram, too, but I go in for lung cancer screening, the last one showed small nodules on my lungs. So, I feel it's important."</p>
Context factors	<p>...</p>	<p>...</p>
Outer context	<p>Many participants thought tools should address common barriers throughout the screening process, including insurance coverage and access.</p> <p>Emphasizing survivorship in messaging and tools may be beneficial to connect with an older cohort of people with HIV.</p>	<p>"It would be kind of messed up for me to go find out ... that I probably need to get screened and then my insurance says you can't get it. You know what I mean? ... So, that would be real helpful if it was to have resources, so if you don't qualify who to call, who to talk to, to get something going."</p> <p>"I mean I guess you know, if I went to a website that was going to talk about, you know, preventative care for HIV-positive people, 'cause that's what it is, and talking about preventative care, for you know, for people living with HIV, that I would want it to sort of be more in line with, you know, survival, and more in line with, you know, this is how we stay healthy, this is what we do to you know, stay alive."</p>

Framework Domain	Theme	Representative Quotations
	Medical skepticism may impact belief in evidence and one's willingness to use LCS tool.	"I have a question about the calculator, who designed it and who determines how and how is that going to impact the result of putting in that information, how skewed is it, let's get real."

LCS = lung cancer screening.

TABLE 3]

Provider Interview Participant Self-Reported Characteristics (n = 10)

Characteristic	No. (%)
Sex	
Female	9 (90)
Male	1 (10)
Age	41 (39–48)
Race (> 1 response allowed)	
American Indian or Alaska Native	0
Asian	1 (10)
Black or African American	0
Native Hawaiian or other Pacific Islander	0
White	9 (90)
Other	0
Hispanic ethnicity	0
Specialty	
Internal medicine or family practice	1 (10)
HIV fellowship	0
Infectious diseases	8 (80)
N/A (advanced practice provider)	1 (10)
Training	
Resident or fellow physician	1 (10)
Attending physician	8 (80)
Advanced practice provider	1 (10)
Time in outpatient setting, %	
< 10	2 (20)
10–25	4 (40)
26–50	2 (20)
51–75	1 (10)
> 75	1 (10)
Time in care of people with HIV infection, %	
< 10	0
10–25	2 (20)
26–50	2 (20)
51–75	2 (20)
> 75	4 (40)

Data are presented as No. (%) or median (interquartile range). N/A = Not applicable.

TABLE 4 |

Key Themes From Provider Interviews Organized by the Health Equity Implementation Framework

Framework Domain	Theme	Representative Quotation
Innovation factors	<p>Providers are supportive of tailored tools that incorporate HIV-related measures and risk to help them facilitate SDM conversations.</p> <p>Providers acknowledge patients with high comorbidity should not be screened, but have concerns about patient-facing tools incorporating measures of comorbidity.</p> <p>Visuals (ie, pictograms and figures) are helpful for facilitating conversations around LCS.</p>	<p>"I think that could be helpful, yes, yes, I think, to see a personalized risk of death would be kind of, I-I'm not sure how well that would be received, but I think to say in general terms that that could be very helpful."</p> <p>"I think that-that, I think that that would be helpful. Because it tailors it to the person I'm talking to, right. Now also, like, if the discussion is about, you know, so many of the discussions I have with people are like, it's fantastic how well controlled your HIV is, and now we get to spend our clinic time talking about other ways that we can reduce your risk of morbidity or death."</p> <p>"I think that people with HIV have a higher risk of all malignancies, and so I-I think that there there's more, like, I-I sort of add screening benefit points to people with HIV for all cancer screening and all chronic disease management."</p> <p>"I just worry again about, that discussion of death, because you know people are so scared about that and I think sometimes it can be hard for them to digest that information in the visit and then respond, you know, like to say, 'What do you mean death? And are you talking about me?' Or how does this apply to me?' Um, and I just sort of worry about the impact that could have on them does that, you know, how ... how do they receive that message?"</p> <p>"I think it's important to say that you have a greater risk of harms. I think that's very important. But the numbers again are a little off-putting, I think..."</p> <p>"I don't think I would probably I-I cannot have a successful conversation with a patient where I say you have a 58% risk of being dead in 5 years. ... I think it's helpful to me as a provider, but I wouldn't share this with the patient."</p> <p>"Yeah, I like this tool a lot. It's just a clean, great way of providing that information. And you know most physicians would say, you know, we want you to be in the gray, we don't want you to have anything. And if we can't get the gray, we want you to be in the green."</p> <p>"Yeah, I think so. And again, I think that, you know, I mean, the value of showing these things to a patient I think goes up as the closer you are to that patient preference decision zone, I think for people who it's very clear that they would not benefit or people who clearly would benefit, you know, these are not as needed but for someone like this who falls in that patient preference zone that, you know, a good pictorial representation is a really great tool."</p>
Clinical encounter	<p>Providers are comfortable with the idea of a tailored screening recommendation and discussing risks and benefits with patients, but were less comfortable explicitly not recommending screening for an eligible patient (based on age and smoking status).</p> <p>Complexities of screening in setting of patient comorbidity may lead providers not to discuss screening if they believe the patient has other more important issues or would not benefit from screening.</p> <p>Providers had concerns about the feasibility of complex and personalized tools given EHR and time limitations.</p>	<p>[When asked about discouraging screening] "That would be hard, that would be hard. I mean 'cause you never want to feel like you're leaving information out, but I also, I don't think I have anybody where I would be like there's 50-50 chance we're gonna die. So I have to think about that."</p> <p>"I think people take recommendations more seriously if they feel like it's been tailored to them specifically, so that would be the big advantage to tailoring it to folks with HIV. But having it only increased by 25% or 20% really is not that much on the scale of things, but helpful, helpful to then it feels more targeted as opposed to random."</p> <p>"You know people have only so much bandwidth and if they're busy going to multiple doctor's appointments to manage their diabetes or their substance abuse or their mental health, and it's a full-time job just managing those health considerations, it's a little tough to say, 'Well, you know why don't you also get lung cancer screening.' It takes a back seat."</p> <p>"Oh, yeah, well, so anybody who's in the last year or two of their life, I'm not going to screen them. So that's, that's consistent with all the, all the cancer screenings ... I don't think we're going to have that conversation. We would if they brought it up. But if they don't bring it up, and I'm not gonna bring it up, and I'm just gonna, usually I'll write in my note, like, you know, screening is not in their best interest at this time."</p> <p>"I'm just trying to think of some of my high comorbidity patients, those are patients who are probably falling into the category of too many other acute issues going on for me to even be recommending the screening. I think that they sort of get triaged. It's not a-as deliberate or thoughtful a process as I might like, but I they are probably the ones getting triaged. But I-I think that, so there's a, there's a de facto discouragement of screening just because their other issues are taking over."</p> <p>"And one of the problems with risk scores that take a lot of input. ... so, so when you put a lot of stuff in the risk, score, it makes them very accurate, but almost nobody in regular clinical practice has all the information to go into the risk score, so then you have a risk score, but you have one that's blank and you're not sure what to do. So keeping it simple is really helpful."</p> <p>"I think, you know, one of the big barriers to using these sort of decision tools in Epic is that they're extremely burdensome for the most part and, um, create a ton of extra work that would have satisfied them to make them go ... I would love some sort of like, uh, when I do a visit with someone</p>

Framework Domain	Theme	Representative Quotation
<p>Inner context: clinic</p>	<p>Knowledge of LCS eligibility criteria is varied among providers.</p> <p>Providers were supportive of an EHR integration for a risk calculator and SDM support tools, particularly dot phrases.</p>	<p>who has smoking on their problem list, I would love to have a pop-up of like, 'Did you think about lung cancer screening?' But not have to, like, satisfy it or answer it or complete it within the visit. Because then it's just like a helpful reminder and not a burden."</p> <p>"I always have to double-check the age group, but I-I know that it's, for people either 50 or 55 above with a specific pack-year history. So all my patients who are smokers when they hit age 50, I go back and I-I remind myself what the age is, and then I calculate their pack-year history and I just double-check the guidelines, 'cause I don't have a ton of, ton of patients were current smokers and even fewer who have more than, like, a 10-pack-year history at this point."</p> <p>"The criteria for screening are a little bit challenging. I have to look them up every time, you know, because trying to figure out how many years ago [a] person quit smoking, if they, if they quit smoking, and how old they are now, and whether they're in the window or out of the window is a bit tricky sometimes."</p> <p>"I think like all tools, it is, it's going to be the most useful if it is the most easily integrated into a visit and a session. So that means having it like in an Epic dot phrase, or in it like built into a note for part of it to pull up. Not saying to providers, 'Hey, you need to have in like, you need to remember this link to a website.'"</p> <p>"So a dot phrase [in Epic EHR] is very helpful. I use that for the atherosclerotic cardiovascular disease model and I use it when I want it, and I don't use it when I don't want it, and I can tailor the message to the patient."</p>

EHR = electronic health record; LCS = lung cancer screening; SDM = shared decision-making.