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Longitudinal retrospective study of real-world adherence to colorectal cancer screening before and after the COVID-19 pandemic in the USA

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ABSTRACT

Introduction At-home stool tests are an increasingly popular practice for colorectal cancer screening, especially when access to healthcare facilities is challenging. However, there is limited information about whether stool tests provide sufficient coverage when patients must undergo repeat testing. This study evaluates repeat preventative stool tests over 2 year periods in a healthcare system with 51 hospitals and over 1000 clinics across seven western US states, before and after the onset of the COVID-19 pandemic.

Methods We conduct a real-world, observational, retrospective and longitudinal study based on electronic medical records. We measure the rate of repeat screening and mean delay in repeat screening among patients who receive an initial stool test. We estimate the changes in the likelihood of colorectal cancer screening using a Cox proportional hazard model.

Results Our sample included 403 085 patients. The share of patients with an initial negative stool test who received a repeat screening ranged from 38% to 49% across different years. Among patients who received a repeat screening, there is a delay of 3 months on average. The volume of stool tests increased during the pandemic: the HR of screening after the onset of the pandemic to that before the pandemic was 1.18 (95% CI (1.15, 1.20), p<0.001).

Conclusions Our findings show that less than 50% of patients received a repeat stool test, creating gaps in their screening coverage. The increase in stool tests during the pandemic is partly due to a substitution away from colonoscopies, underscoring the increasing importance of stool tests in CRC screening. Programmes that aim to increase CRC screening uptake should focus on repeated testing after an initial screening.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Patients, especially those with limited access to healthcare facilities, are substituting towards stool tests and away from colonoscopies. This trend accelerated after the onset of the COVID-19 pandemic.

WHAT THIS STUDY ADDS

⇒ This study examines long-term adherence to screening guidelines using real-world data. We find that most patients do not undergo the recommended repeat screening after their initial stool test, demonstrating an important drawback of these tests.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Although stool tests provide a more accessible colorectal cancer screening procedure, non-adherence to annual testing creates gaps in screening coverage and diminishes their benefits. Healthcare providers and policymakers should invest in improving long-term adherence to screening through outreach, policies and programmes.

INTRODUCTION

Colorectal cancer (CRC) is one of the most common and deadly cancers: an estimated 52 550 people in the USA were estimated to die of CRC in 2023.[1] Clinical evidence overwhelmingly demonstrates that timely CRC screening reduces patient mortality.[2–4] Unfortunately, despite the high prevalence of CRC and the substantial benefit of CRC screening, current rates of CRC screening remain below United States Preventive Services Task Force (USPSTF) 2016 guidelines.[5]

Colonoscopies have been the gold standard of CRC screening for many years, but stool tests conducted at home, primarily FIT (faecal immunochemical test) and FOBT (faecal occult blood test), are an increasingly common CRC testing method. FIT/FOBT tests are easier to access, less invasive and less resource intensive for the patient and the health system than colonoscopies. However, their diagnostic capabilities are more limited, and so FIT/FOBT tests are recommended annually.[6 7] Given the higher frequency of stool tests necessary to be compliant with current guidelines, there is a higher risk of gaps in screening coverage as patients may fail

to adhere to the annual testing regimen. Whether or not stool tests are an effective alternative depends crucially on whether patients receive repeat screenings.

Currently, there is limited research on whether patients undergo repeat stool tests following initial negative test results.[8 9] If present, these gaps in screening coverage could limit the benefits of stool tests compared with colonoscopies.

The purpose of this paper is to document the rates of repeat preventative stool tests in a large, community-based healthcare setting that spans multiple US states. We examine repeat testing rates both before and during the COVID-19 pandemic. The pandemic is a salient time to conduct this study because it resulted in a dramatic decrease in colonoscopies, which were partially replaced by stool tests.[10–12] This partial replacement of colonoscopies by stool tests has led other studies to conclude that stool tests mitigated gaps in CRC screening during the pandemic.[10 13] But gaps may persist if patients do not undergo repeat testing.

METHODOLOGY

Data source, study cohort and study period

Our primary data source is the electronic medical records (EMR) of patients receiving healthcare services at Providence St. Joseph Health (PSJH). PSJH is a large community-based health system that serves more than two million patients with 51 hospitals and over 1000 clinics across seven western US states. We access the EMR across all the sites through a cloud data warehouse, which is one of the largest implementations of an integrated electronic health record system in the USA. The EMR contains detailed information about a broad range of patient characteristics, services, diagnoses and treatments for any patient who has received care at PJSH. In addition, the EMR includes unique patient identifiers that allow us to link patients over time and across different healthcare visits.

To inform this study, we include data from patients who (1) had at least one primary care encounter at any PSJH facilities between 1 January 2016, and 31 December 2019, and (2) had not been previously diagnosed with CRC. We include only patients with prior primary care visits to ensure that these patients are regularly seeking care at our healthcare system, thereby minimising sample attrition. Because our object is preventative colorectal screening, we exclude patients who have a confirmed CRC diagnosis and thus are not eligible for preventative screening, from our analysis. To identify such patients, we examine patient medical records going back to 1 January 2010. A CRC diagnosis is determined based on healthcare encounters with the corresponding ICD-10 (International Classification of Diseases, Tenth Revision) codes (see key definitions below). For similar reasons, we also excluded patients who received a diagnostic CRC screening between 1 January 2010 and 31 December 2015. A CRC test is considered diagnostic (instead of screening) if the procedure is labelled diagnostic by the healthcare provider, as recorded in the EMR. In online supplemental figure A1, we provide a Consolidated Standards of Reporting Trials (CONSORT) diagram that illustrates specific exclusions and resulting cohort sizes. Our baseline study cohort consists of 403 085 patients.

We divide our analysis into two periods based on the onset of the COVID-19 pandemic. The 'pre-COVID-19 onset' period is from 1 January 2018 to 29 February 2020, and the 'post-COVID-19 onset' period is from 1 March 2020 to 28 February 2022. Analyses were conducted using R V.4.3.1.

Key definitions and variables

On a given date, a patient is *eligible* for CRC screening if they have not been previously diagnosed with CRC, are between the ages of 45 and 75 and are not already up to date with their screening. Our patient eligibility criteria are based on 2016 USPSTF guidelines.[5] In online supplemental figure A2, we present the number of patients eligible for CRC screening in each month of our study period. A patient can receive CRC screening using three procedures: colonoscopy, sigmoidoscopy or a FOBT/FIT stool test. Based on current USPSTF guidelines, we consider a patient *up to date* with their CRC screening if they have received a colonoscopy within 10 years, a sigmoidoscopy within 5 years or a FOBT/FIT within 1 year of the given date.[6] If a patient is eligible for CRC screening but is not up to date with their screening, we refer to them as *non-adherent* patients.

A *repeat screening* occurs when an eligible patient receives an additional screening at least 1 year after their initial negative FOBT/FIT. Conditional on a repeat screening, a *delay* in screening is the time between when a repeat screening was due and when the repeat screening occurred. See online supplemental figure A3 for a hypothetical vignette that illustrates these concepts and definitions.

If a patient receives a positive test result or is diagnosed with CRC, they are no longer eligible for repeat preventative screening. A patient is *diagnosed* with CRC if they have any healthcare encounter with primary ICD-10 codes C18-21. The date of diagnosis for a patient is the earliest date of a healthcare encounter with a CRC diagnosis. We determine a patient's vital status and date of death (if deceased) using three data sources: Surveillance, Epidemiology and End Results cancer registry; social security index and PSJH electronic health records.

We consider several important demographics: sex (male, female), race (American Indian/Alaska Native (AI/AN), Asian, Black, Pacific Islander, White, Unknown), geographic location (urban, rural), insurance type (Commercial, Medicaid, Medicare, Other Government, Other) and age at screening (under 50, 50–64 years and 65–75 years).

Ethics approval statement

This study involves human participants and was approved by the Providence Institutional Review Board (ID Number: STUDY2022000240).

Patient and public involvement

Our research question was motivated by the responses of patients and community members in a distinct research study that investigates CRC screening knowledge and barriers to screening via surveys and focus groups (this study is currently under review). Patients were not directly involved in the research design or analysis of this study. Results from the current study will be disseminated to the public in collaboration with our community health team and our long-term community partners. We will also reach patients through our health system outreach pathways.

Analyses

We examine descriptive trends in when and how often patients receive a *repeat screening* after an initial FOBT/FIT. To limit the role of censoring, we examine whether patients receive a repeat screening within 1 year of when they are eligible for a screening. Follow-up screenings may be done by any procedure.

We also examine how the time to CRC screening changes after the onset of the COVID-19 pandemic using a Cox proportional hazard model with a time-varying hazard. Specifically, the hazard of receiving a CRC screening during a calendar year y is:

$$\gamma_y(t \mid X) = \gamma_0(t) \exp\left(\beta^{\text{covid}}\, 1\{y > \text{ Feb 2020}\} + \alpha X\right)$$

where $1\{y >$ Feb 2020$\}$ denotes the period after the onset of the COVID-19 pandemic and X are control variables. The parameter β^{covid} captures the extent to which the hazard of screening changed after the onset of the COVID-19 pandemic. We examine CRC screening by all procedures together and by different procedures separately. We include sex, race, urban–rural status, age and insurance type of the patient as controls. We estimate the parameters of the model using Maximum Likelihood. We perform log-rank tests to determine the statistical significance of β^{covid}. SEs are computed using the inverse of the Hessian of the log-likelihood function, as is standard in the literature[14] (see online supplemental table A1 for definitions and descriptive statistics of these key control variables)

RESULTS

Gaps in FOBT/FIT coverage

In figure 1, we present the share of patients who received a repeat screening within 1 year of the USPSTF-recommended screening date (see online supplemental figure A2 for the number of patients eligible for CRC screening in each 2 month period). We find that approximately 50% of patients received a repeat screening in the pre-COVID-19 onset period. The share of repeat screening declines slightly to 38% before the onset of the COVID-19 pandemic and remains below 50% throughout our study sample. These results highlight that most patients do not consistently repeat their annual FOBT/FIT screening.

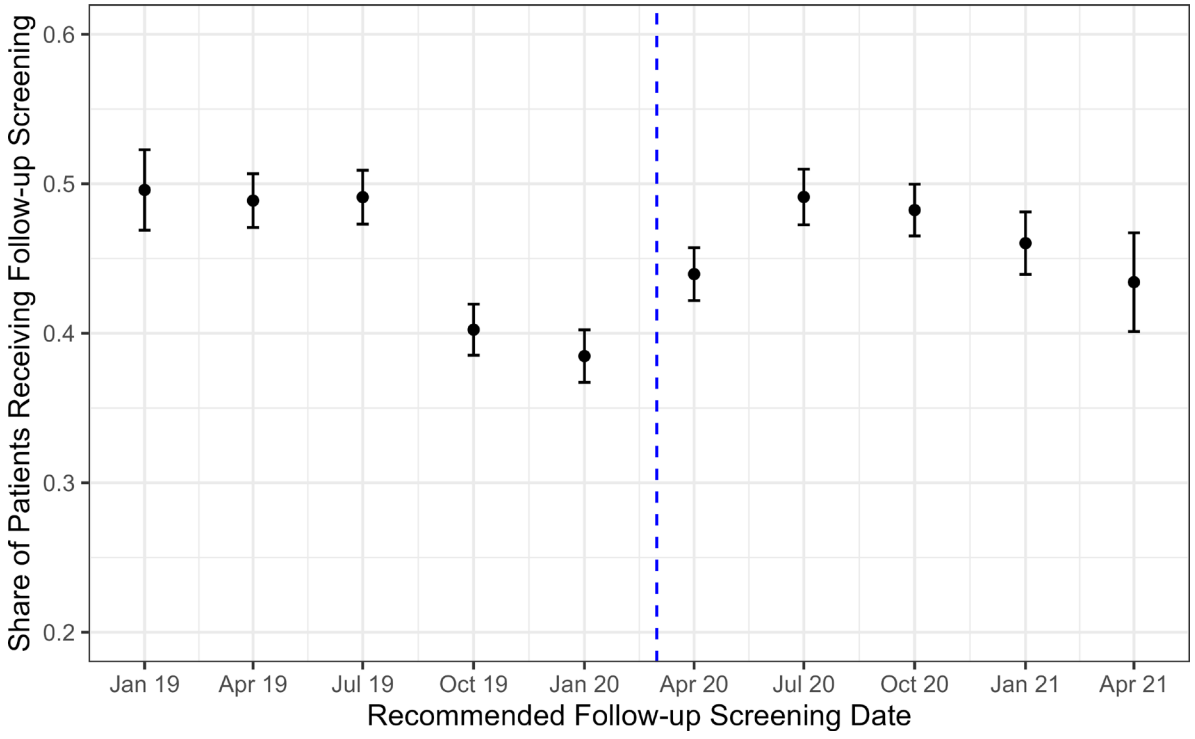

Figure 1 Share of patients receiving a follow-up FOBT/FIT screening. FIT, faecal immunochemical test; FOBT, faecal occult blood test.

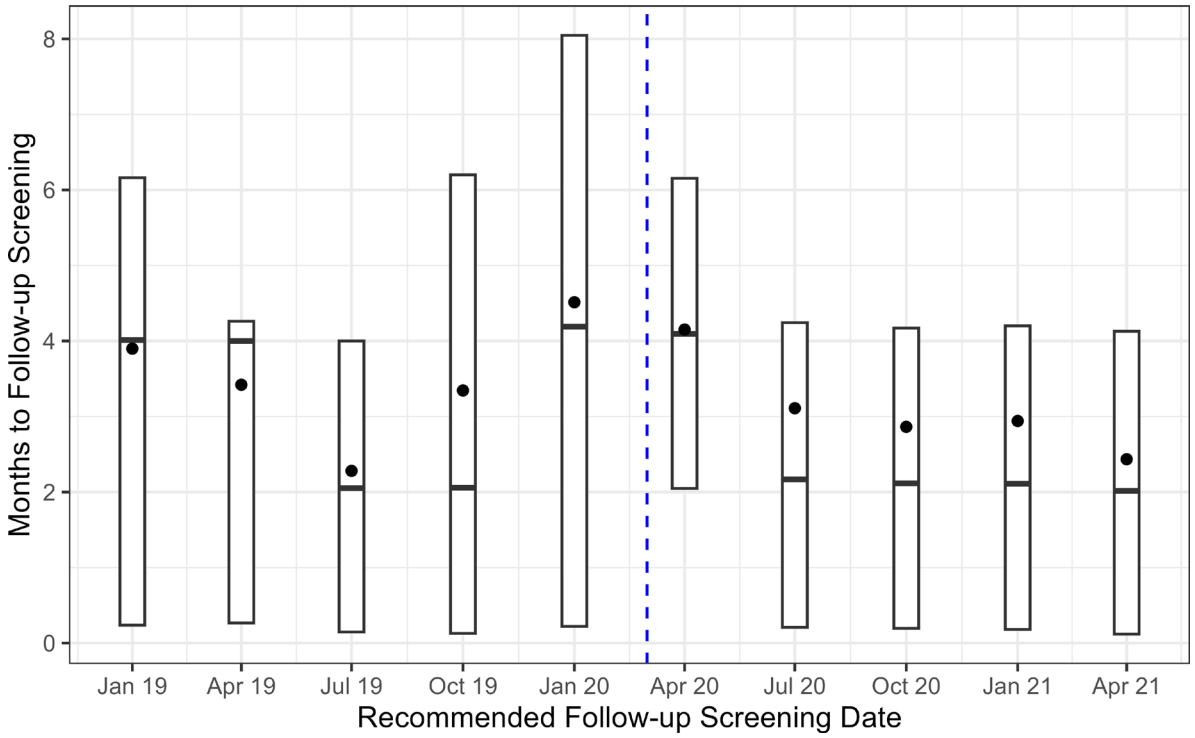

Figure 2 Delay in recommended follow-up FOBT/FIT screening. FIT, faecal immunochemical test; FOBT, faecal occult blood test.

Furthermore, among patients who do a repeat screening, there is a statistically significant (p<0.001) and practically meaningful delay on average. Figure 2 shows that among the 50% of patients who do get any repeat screening, patients on average receive a repeat screening 3 months after they are due for a repeat screening. This repeat screening delay increased to about 5 months during the COVID-19 pandemic. The 5 month delay is almost half as long as the preventative screening period of stool tests (12 months).

Trends in CRC Screening

In figure 3, we examine the volume of different CRC procedures. Before the COVID-19 pandemic, with over

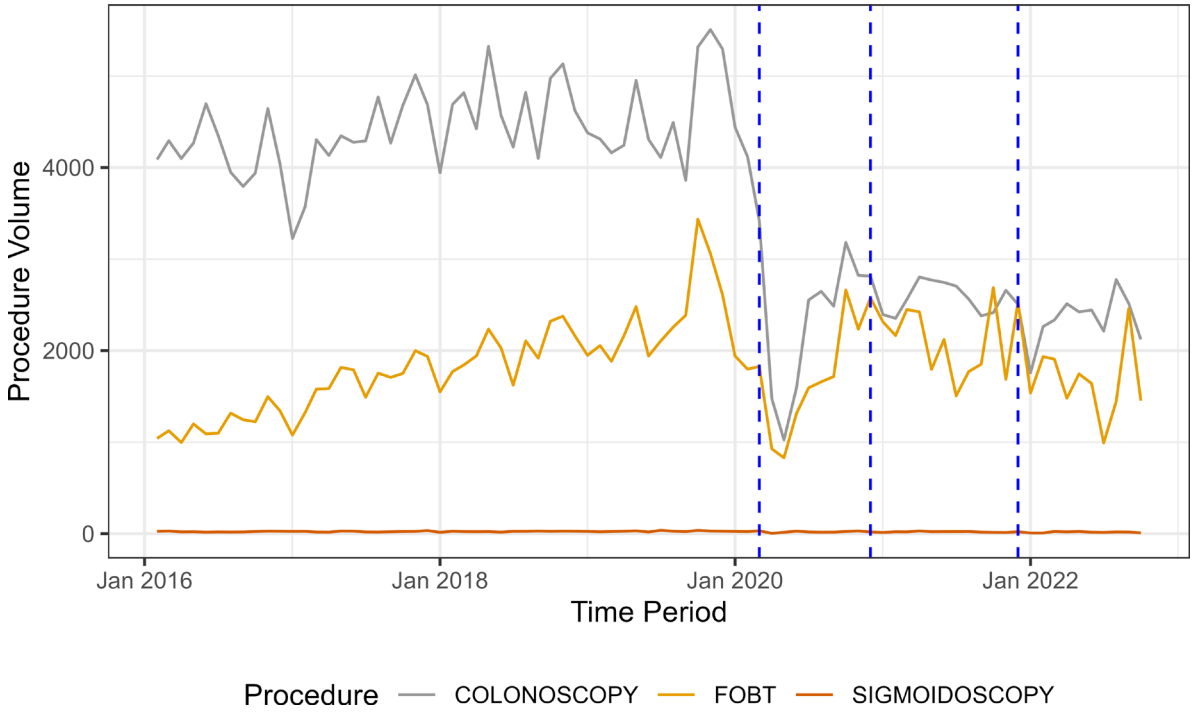

Figure 3 Volume of different CRC screening procedures over time. CRC, colorectal cancer; FOBT, faecal occult blood test.

Table 1 Estimates of change in hazard of CRC screening after the onset of COVID-19 pandemic

Post-COVID-19 onset (β^{covid}) Comparison group: pre-COVID-19 onset	Unadjusted HR, 95% CI, p value	Adjusted* HR, 95% CI, p value
All procedures	0.46 (0.45, 0.46)	0.66 (0.65, 0.67)
	<0.001	<0.001
Colonoscopies	0.37 (0.36, 0.38)	0.49 (0.48, 0.50)
	<0.001	<0.001
FIT/FOBT	0.78 (0.76, 0.79)	1.18 (1.15, 1.20)
	<0.001	<0.001

*Includes covariates: sex, race, urban/rural status, insurance type and age at screening.
FIT, faecal immunochemical test; FOBT, faecal occult blood test.

4000 procedures per year, the most popular screening procedure was colonoscopy. The volume of colonoscopies declined substantially after the onset of the COVID-19 pandemic and remained low till the end of our study period. In contrast, the volume of at-home stool tests was increasing before the pandemic and bounced back to pre-pandemic levels by the end of 2021. During the last year of our study period, the volume of colonoscopies and FOBT/FIT tests was comparable. The volume of sigmoidoscopies in our study population was negligible throughout the study period.

We statistically analyse changes in screening patterns using the estimates from our hazard model, as presented in table 1. We find that the hazard of CRC screening by all procedures significantly decreases by a large magnitude after the onset of the COVID-19 pandemic in 2020. However, the decrease in the likelihood of screening was largely associated with a decline in the hazard of receiving a colonoscopy. The probability of receiving FIT/FOBT was estimated to be similar or even higher after the onset of the COVID-19 pandemic (table 1).

The decline in volume of CRC screening procedures corresponded with a decline in the screening rates of eligible patients (figure 4). Prior to the onset of the COVID-19 pandemic, the screening rates of eligible patients were approximately 8% for a 2 month period. Following the onset of the COVID-19 pandemic and the associated stay-at-home policies in March 2020, 2 month screening rates dropped to 2%. The 2 month screening rates remained below pre-pandemic onset levels until the end of our study period.

DISCUSSION

Stool tests offer an accessible and increasingly popular alternative to colonoscopies for CRC screening.[15] Rural, low-income, uninsured and Black patients have experienced documented difficulties accessing colonoscopies for an array of reasons such as lack of insurance, language barriers, financial constraints and cumbersome travel.[16–18] FOBT/FIT appear to be effective alternatives to colonoscopy and might be especially useful for patients with limited access to care.

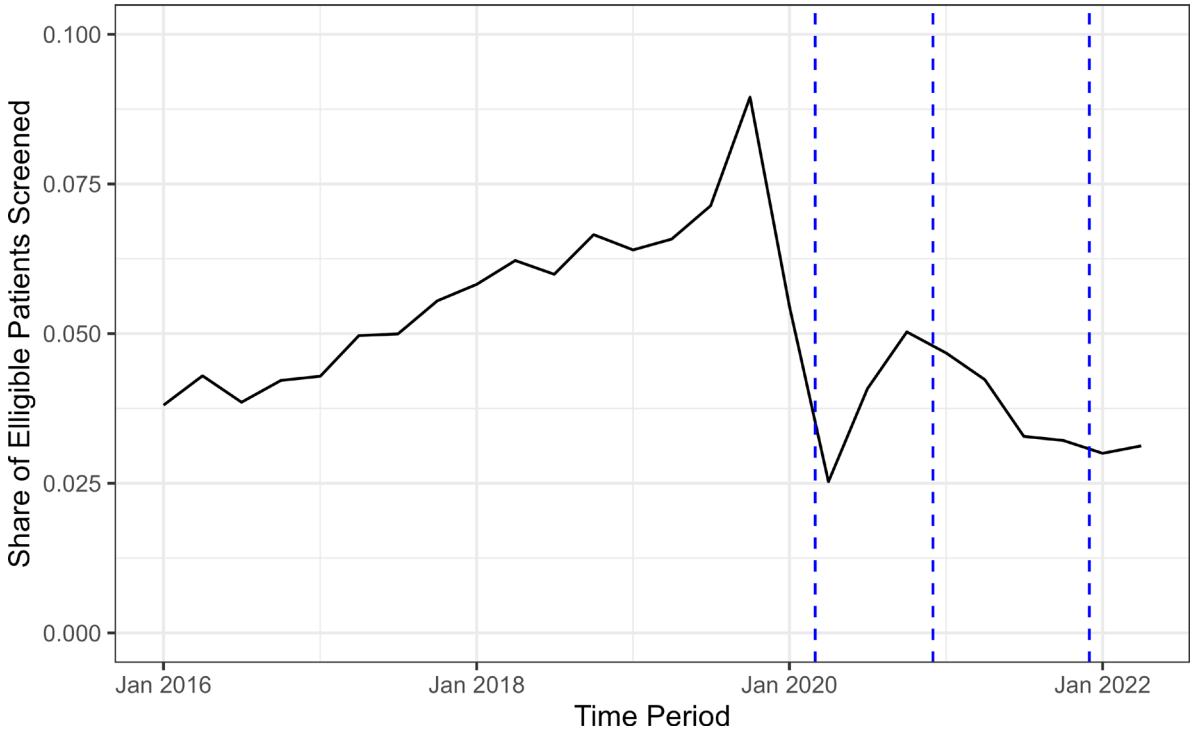

Figure 4 Unadjusted mean share of eligible patients screened over time.

However, FOBT/FIT tests must be repeated annually, whereas colonoscopies for average risk patients only need to be repeated every 10 years. Therefore, even though FOBT/FIT are more physically accessible, the higher frequency of testing can make it more challenging for patients to adhere to. In addition, a diagnostic colonoscopy is still needed to follow up a positive FOBT/FIT test.

Our results on multiyear adherence show that more than 50% of patients did not get a repeat screening test within a year, and the minority of patients who did get a second screening often got it 2–5 months later than they should have, based on clinical guidelines. For a screening test that should be administered annually, a 2–5 month delay in screening represents 17%–42% of the screening period; a meaningful amount of time to be without screening. Our results are qualitatively consistent with several randomised studies on repeat faecal tests, such as the STOP CRC trial.[19–23] Our study, with its large and diverse patient population, further generalises the insight that patients may have gaps in their screening coverage after an initial FOBT/FIT due to delays in recommended repeat screening. We also find slightly larger gaps and longer delays than in studies of the randomised trials, suggesting that non-adherence may be an even larger issue in a real-world setting outside the trial context. These gaps could delay detection of CRC and subsequent treatment, potentially resulting in higher mortality. [24]These gaps are particularly important as more and more patients use stool tests instead of colonoscopes for CRC screening. This shift towards stool tests was accelerated during the COVID-19 pandemic, as shown by our results and the extant literature.[2–4 10–13] Given this increase in stool tests, it will be increasingly important to focus on improving long-term adherence to screening through outreach, policies and programmes.[19 25]

Limitations

Our study has two important limitations. First, we experienced sample attrition for patients who stopped seeking care at our institutions. However, it is likely sample attrition did not meaningfully influence our results given the large size of the health system. In addition, it is difficult to distinguish between attrition of patients who are no longer seeking care at Providence institutions versus those who are still Providence system patients but could not or chose not to have a follow-up healthcare visit within our study time frame. We attempted to mitigate this limitation by selecting patients who had established care with our health system by having at least one primary care visit.

Second, we are unable to speak to the downstream effects of reduced CRC screening such as treatment, stage migration and mortality because of the relatively short time horizon of the present study. The impact of changing screening modalities on CRC diagnosis, treatment and health outcomes is of utmost importance. Future studies on how these gaps in screening translate into downstream outcomes are critical.

CONCLUSIONS

We document low rates of follow-up CRC screening after an initial stool test. Although stool tests are resilient to healthcare access barriers such as the COVID-19 pandemic, they come at the cost of gaps in screening when patients do not adhere to the annual testing regimen.

From individual physicians to policymakers, decisions regarding CRC screening procedures should take frequency of testing and long-term adherence into account. Physicians in clinical practice should discuss the pros and cons of stool tests with their patients to facilitate informed, shared decision making.[26] These discussions should not only consider screening at a given point in time, but also how choices today can influence long-term screening needs. Healthcare systems should develop and incorporate practices to minimise delays in repeat screening.

Contributors HG, SJW, JBW and AJB conceived the study. HG, RAH, AV, and CB curated the data. HG, RAH, SJW, and CB were responsible for the methodology. HG, RAH, AV, and CB validated the data. HG, RAH and CB performed the formal analyses. HG, RAH, SJW, CB, JBW and AJB prepared the original draft of the manuscript. HG, RAH, SJW, AV, CB, JBW and AJB reviewed and edited the manuscript. HG generated the original figures and tables. SJW and AJB supervised the analyses, manuscript writing and generation of figures and tables. RAH and SJW handled project administration. SJW and AJB acquired the funding. HG and SJW accept full responsibility for the finished work and/or the conduct of the study, had access to the data and controlled the decision to publish. HG is the guarantor of the paper. The corresponding author attests that all listed authors meet authorship criteria and that no others meeting the criteria have been omitted.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not applicable.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available upon reasonable request. Data will be available upon reasonable request.

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