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Prevalence and predictors of cancer screening in transgender and gender nonbinary individuals

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ABSTRACT

Background: Current cancer screening guidelines for transgender individuals are guided primarily by expert opinion, and are extrapolated from guidelines for cisgender populations, despite the additional unique risks that transgender populations face in cancer risk and cancer care.

Aims: We examined adherence to current recommended screening guidelines as well as drivers of cancer screening in 192 transgender and gender-nonbinary (TGNB) individuals participating in Project AFFIRM, a multi-site longitudinal cohort study of TGNB individuals.

Methods: We used a chi-squared analysis to look for significant associations between predictors and adherence to breast, cervical, prostate and colon cancer screening. We analyzed predictors by 3 different categories: sex/gender identity, healthcare access, and socioeconomic status.

Results: Screening rates were low for breast, cervical, prostate and colon cancer in TGNB populations compared to national rates for cisgender populations. Among several significant predictors, gender-affirming surgery (hysterectomy) (p -value = <0.0001) and telling others they are transgender at a younger age (< 18) (p -value = 0.0344) were associated with increased screening adherence, while having HIV was associated with decreased screening adherence (p -value = 0.0045).

Discussion: Our results suggest that interacting with the healthcare system to obtain comprehensive cancer screening can be difficult to navigate among the other healthcare needs of TGNB individuals both on an individual and systems level. Future efforts to mitigate the barriers to screening adherence should be targeted at the healthcare system level.

KEYWORDS

Cancer; guidelines; hormones; screening; transgender

Introduction

As of 2016, there are an estimated 1.4 million adults in the U.S. that identify as transgender which comprises 0.6% of the U.S adult population (Flores et al., 2016), and this number is expected to increase in the future (Meerwijk & Sevelius, 2017). Given the absence of gender identity data in many databases, there is limited research regarding transgender cancer care (Cortina, 2022; Martinez et al., 2022). Transgender and nonbinary (TGNB) individuals face discrimination that can lead to delays in cancer screening (Scime, 2019). A comparison of transgender patients to cisgender patients in the National Cancer Database (NCDB)

showed that for many cancer types, transgender patients may be diagnosed at later stages, be less likely to receive treatment, and have worse survival (Jackson et al., 2021). The need for evidence-based, tailored screening and service recommendations is more paramount than ever, particularly due to the health disparities that TGNB individuals experience (Committee on Understanding the Well-Being of Sexual and Gender Diverse Populations, Committee on Population, Division of Behavioral and Social Sciences and Education, & National Academies of Sciences, Engineering, and Medicine, 2020).

Currently, screening guidelines for various cancers including, breast, cervical, prostate, and

colorectal cancer in TGNB individuals are not evidence-based, but rather extrapolated from guidelines developed for cisgender individuals. For instance, the Gender Affirming Health Program at the University of California, San Francisco uses the GRADE scoring system to assess quality of evidence to support their most current guidelines for primary and gender-affirming care of TGNB individuals, and some screening recommendations had supporting evidence that were categorized as “Weak” (*General Approach to Cancer Screening in Transgender People | Gender Affirming Health Program*, n.d.). This is in addition to the lack of consensus on certain cisgender cancer screening guidelines from which transgender screening guidelines are extrapolated. One example of this is the lack of general agreement for breast cancer screening guidelines in cisgender individuals (screening beginning at 40 versus 50 years old) (*Screening for Breast Cancer in Transgender Women | Transgender Care*, n.d.).

Furthermore, there are inconsistencies between professional organizations that have issued cancer screening guidelines and recommendations for TGNB people and organizations that have failed to mention TGNB individuals altogether. Some agencies offer guidelines but are unable to find sufficient evidence to create tailored recommendations for transgender, gender nonbinary, or gender nonconforming populations (Sterling & Garcia, 2020). Another issue in the delivery of screening guidelines is the use of sex and gender terms inconsistently, creating more uncertainty surrounding application of these guidelines to TGNB individuals (Caughey et al., 2021). On the other hand, some agencies are more specific in their guidelines and further stratify on gender-affirming hormone therapy (GAHT) use and surgeries in creation of their guidelines, allowing for more tailored cancer care (*Guidelines for the Primary and Gender-Affirming Care of Transgender and Gender Nonbinary People | Transgender Care*, n.d.). Yet because of the lack of evidence, currently available guidelines rely primarily on expert opinion, so further evidence will be useful to inform continued development of these guidelines. Below we summarize current guidelines for breast, cervical, prostate, and colorectal cancers (Table 1).

Despite the lack of evidence and inconsistencies in current cancer screening guidelines for transgender people, in this study we sought to assess adherence to these guidelines in transgender women, transgender men, and nonbinary individuals (TGNB) and to identify predictors of adherence.

Methods

Participants

We analyzed baseline and 3-year follow-up data from Project AFFIRM, a multi-site longitudinal cohort study of TGNB individuals studying gender-identity development across the lifespan. Study staff recruited participants from New York, San Francisco, and Atlanta using venue-based recruitment and purposive quotal sampling. The study spanned 4 years, with an annual assessment per year and the last wave was added to study the impact of the coronavirus (COVID-19) pandemic (Valente et al., 2020). We included individuals who were 16 years of age or older, identified as transgender or nonbinary, and were fluent in English or Spanish, while we excluded individuals who were planning to leave the study region three years following recruitment, significantly cognitively impaired, or unable/unwilling to provide contact information for follow up. Trained interviewers collected data using structured interviews in either English or Spanish at baseline in 2016–17, and at 1- and 2-year follow up in the study cities (Kidd et al., 2019). Due to the COVID-19 pandemic, the fourth wave of data collection consisted of an online, self-administered survey in the Spring of 2020. We included only individuals who were recruited at baseline and responded to the fourth wave, which included questions regarding various cancer screenings ($n = 192$).

We applied the WPATH SOC-8 guidelines in this study for breast and cervical cancer which recommend following cisgender women screening guidelines; for these we followed the USPSTF guidelines. For prostate cancer we applied the UCSF guidelines which recommends following guidelines for non-transgender men, in which we used the American Cancer Society guidelines. We

Table 1. Current recommended cancer screening practices in transgender individuals among various organizations.

Population	Cancer Site		
	Breast (Clarke et al., 2022)	Cervix	Prostate
Transgender men	<p><i>Patients that have had top surgery</i> University of California San Francisco: Dialogue with patients about risks (<i>Guidelines for the Primary and Gender-Affirming Care of Transgender and Gender Nonbinary People Transgender Care, n.d.</i>)</p> <p>Fenway Health: Consider yearly chest examinations (February 2015, 2023)</p> <p><i>Patients without top surgery</i> University Hospitals Cleveland Medical Center, University of California San Francisco, Fenway Health, Endocrine Society Clinical Practice Guidelines, WPATH SOC-8: Follow cisgender women screening guidelines (<i>Breast Cancer Screening Guidelines – Transgender Cancer Screening for Women and Men – Cleveland OH University Hospitals, n.d.</i>; <i>Guidelines for the Primary and Gender-Affirming Care of Transgender and Gender Nonbinary People Transgender Care, n.d.</i>; February 2015, 2023; Hembree et al., 2017; Coleman et al., 2022)</p>	<p>WPATH SOC-8, University of California San Francisco: Follow cisgender women guidelines for cervical cancer screening (Coleman et al., 2022; <i>Guidelines for the Primary and Gender-Affirming Care of Transgender and Gender Nonbinary People Transgender Care, n.d.</i>)</p>	<p>No recommendations for this population</p> <p>No recommendations for this population</p>
Transgender women	<p>University Hospitals Cleveland Medical Center, University of California San Francisco: Screening mammography every 2 years if 50 or older and at least 5 years of GAHT (<i>Breast Cancer Screening Guidelines – Transgender Cancer Screening for Women and Men – Cleveland OH University Hospitals, n.d.</i>; <i>Guidelines for the Primary and Gender-Affirming Care of Transgender and Gender Nonbinary People Transgender Care, n.d.</i>)</p> <p>Endocrine Society Clinical Practice Guideline: Follow cisgender women guidelines (Hembree et al., 2017)</p> <p>WPATH SOC-8: Follow local breast cancer screening guidelines developed for cisgender women for transgender people who have taken estrogens, taking into consideration length of time of GAHT, dosing, current age, and age GAHT initiated (Coleman et al., 2022)</p>	<p>No recommendations for this population</p>	<p>Endocrine Society Clinical Practice Guideline: Transgender women treated with estrogens should follow individualized screening according to personal risk for prostate cancer (Hembree et al., 2017)</p> <p>University of California San Francisco: The decision to screen for prostate cancer should be based on guidelines for non-transgender men (<i>Prostate and Testicular Cancer Considerations in Transgender Women Gender Affirming Health Program, n.d.</i>)</p> <p>No recommendations for this population</p>
Cisgender guidelines (for reference)	<p>American Cancer Society: Women between 40 and 44 have the option to start screening with a mammogram every year, women 45 to 54 should get mammograms every year, women 55 and older can switch to a mammogram every other year, or can choose yearly mammograms (ACS Breast Cancer Screening Guidelines, 2023)</p> <p>USPSTF: Biennial screening mammography for women aged 40 to 74 years (<i>Recommendation: Breast Cancer: Screening United States Preventive Services Taskforce, n.d.</i>)</p> <p>American College of Radiology: Annual screening mammography or DBT (with accompanying planar or synthesized 2-D images) is recommended starting at 40 (Mainiero et al., 2017)</p>	<p>USPSTF: screening for cervical cancer should be conducted every 3 years with cervical cytology for cisgender women aged 21 to 29 years old. Cisgender women who are between 30 and 65 years old, it is recommended that cervical cytology be done every 3 years, hrHPV testing done every 5 years, or hrHPV testing done in combination with cytology every 5 years. (US Preventive Services Task Force, Curry et al., 2018)</p> <p>American Cancer Society: HPV test alone every 5 years for everyone with a cervix from age 25 to 65. If unable to HPV test alone, can screen with HPV/PAP cotest every 5 years or PAP test every 3 years (New ACS Cervical Cancer Screening Guideline—NCI, 2020)</p>	<p>USPSTF: Decision to screen for prostate cancer using prostate-specific antigen-based screening should be an individual one for cisgender men age 55 to 69, cisgender men 70 or older should not screen for prostate cancer (US Preventive Services Task Force, Grossman et al., 2018)</p> <p>American Cancer Society: Recommends men to make an informed decision with their healthcare provider about whether or not to screen for prostate cancer. This discussion should take place at age 50 for men who are at average risk (<i>American Cancer Society Recommendations for Prostate Cancer Early Detection, n.d.</i>)</p> <p>USPSTF: Recommends starting screening at 45 using either: high-sensitivity gFOBT or FIT every year, sDNA-FIT every 1 to 3 years, CT colonography every 5 years, flexible sigmoidoscopy every 5 years, flexible sigmoidoscopy every 10 years+FIT every year, colonoscopy screening every 10 years (Davidson et al., 2021)</p> <p>American Cancer Society: Adults aged 45 years or older undergo regular screening with a stool exam or a visual exam (<i>Colorectal Cancer Screening Guidelines, n.d.</i>)</p>

followed the USPSTF guidelines for colorectal cancer screening. We focus on patient reported screening, although we recognize that adherence to screening guidelines involves not only the patient agreeing to be screened but also a provider offering a screen, and other upstream factors such as access to care and health insurance.

Cancer screening outcomes

We assessed cancer-specific screening adherence by asking if participants ever had any of various cancer screenings (mammogram, HPV/PAP test, PSA test, colonoscopy). For breast cancer, for instance, we considered a positive screen if participants reported having a mammogram. For each screening, individuals whose most recent screening occurred prior to the age at which they first began to feel that they were transgender (even if they did not know the word for it) were excluded: 5 for breast cancer screening, 22 for cervical cancer screening, 3 for prostate cancer screening, and 4 for colon cancer screening. Additionally, those remaining in the dataset whose age at baseline was younger than the recommended age of screening were excluded from analysis per screening type: 130 for breast cancer screening (below age 40), 23 for cervical cancer screening (below age 21), 162 under the age of 50 for prostate cancer screening, and 142 under the age of 45 for colon cancer screening. These age guidelines were applied to all groups since some groups do not yet have age specific guidelines as displayed in [Table 1](#).

Predictors

We used data from the three previous collection waves to identify possible predictors of screening adherence. Baseline variables that we considered static (did not vary over time), included ethnicity (Hispanic vs non-Hispanic), race (White, other), sex assigned at birth (Male or Female), age at which they first thought their gender differed from their sex assigned at birth, age at which they first thought they were transgender, and age they began to tell others they were transgender. For static variables we used baseline data as the responses did not change over the course of the three waves.

For dynamic variables that varied over time, we created a composite variable to indicate whether or not the participant ever experienced the predictor over the course of the three waves. In this context, we define predictors broadly as any factor that may be associated with screening adherence. Dynamic predictors included: difficulty finding housing, difficulty finding employment, having a place to go for healthcare, not being able to go to the doctor because of cost, not going to the doctor to avoid mistreatment as a transgender person, having a doctor who is knowledgeable about transgender health, currently undergoing GAHT, HIV status, having gender affirming surgeries (top surgery, hysterectomy), current employment status (employed full-time, employed part-time, student, self-employed, out of work for more than a year, out of work for less than a year, homemaker, retired), annual personal income, housing in the last 12 months (in house/apartment/condo they own, in house/apartment/condo they rent, with other person who pays for housing, with family, in student housing, with friends or family temporarily, homeless, in a shelter, in a group home, in a nursing facility, other) and current gender identity (transgender woman, transgender man, non-binary/genderqueer/another) which we used baseline data for. We recoded current employment status as employed versus unemployed, annual personal income as \$24,000 or more versus less than \$24,000, and housing in the past 12 months as stable versus not stable. We analyzed predictors in 3 different categories: sex/gender identity (sex assigned at birth, gender identity, age began to feel gender was different from assigned birth sex, age started to think they were transgender, age they started to tell others they were transgender, GAHT, gender affirming surgery), healthcare (have a usual place for healthcare, did not see a doctor because of cost, did not see a doctor to avoid disrespect or mistreatment as a transgender person, healthcare provider who is knowledgeable about transgender health, HIV status), and socioeconomic status (ethnicity, race, employment status, income, stable housing, difficulty finding housing, difficulty finding employment).

Statistical analysis

We used a chi-squared analysis to look for significant associations between predictors and adherence to screening, by cancer type. If during the analyses 20% or more of the expected cell counts were below 5, we used Fisher's exact test instead. In addition, we conducted sensitivity analyses, stratified by sex assigned at birth and GAHT status, gender affirming surgery and GAHT status, and sex assigned at birth and gender affirming surgery to further understand how these three variables may influence each other. We assessed adherence to screening of individuals who were eligible for screening based on the age guidelines stated above.

Data availability statement

The authors generated the data which are available upon request from the corresponding author.

Results

Overall, we included 192 respondents in the analysis for this study. Respondents ranged in age from 16 to 69 years with an average age of 34 years old. Over half (62.0%) identified as white. Fifty-nine percent (59.9%) of the sample were assigned female at birth; 34.9% identified as a transgender woman, 37.0% as a transgender man, and 28.1% as non-binary, genderqueer, or another gender. Additional information describing the summary characteristics of the overall study sample at baseline according to sex and gender identity, healthcare, and socioeconomic predictors are in [Tables 2–4](#).

Of the individuals eligible to be screened for breast cancer ($n=57$), 50.9% of individuals received a mammogram ($n=29$). Respondents who were assigned female sex at birth were more likely to receive a mammogram ($p\text{-value} = 0.0004$) than those assigned male at birth ([Table 2](#)). Stratified by sex assigned at birth, among TGNB individuals who were assigned male at birth, 37.9% of those undergoing GAHT received a mammogram versus 22.2% among those who were not undergoing GAHT. Among TGNB individuals who were assigned female at birth, 80.0%

of those undergoing GAHT received a mammogram versus 100.0% among those who were not undergoing GAHT ([Table 5](#)). Transgender women were less likely to receive a mammogram compared to transgender men ($p\text{-value} = 0.0028$) ([Table 2](#)). Those who were HIV-positive were less likely to have received a mammogram than those who were HIV negative ($p\text{-value} = 0.0045$) ([Table 3](#)).

Of the individuals eligible to be screened for cervical cancer ($n=147$), 48.3% received an HPV/PAP test ($n=71$). Respondents who were assigned female sex at birth were more likely to receive an HPV/PAP test ($p\text{-value} = <0.0001$) than those assigned male at birth ([Table 2](#)). Stratified by sex assigned at birth, among TGNB individuals who were assigned male at birth, 15.5% of those undergoing GAHT received a PAP test versus 8.3% who were not undergoing GAHT. Among TGNB individuals who were assigned female at birth, 82.5% of those undergoing GAHT received a PAP test versus 64.3% who were not undergoing GAHT ([Table 5](#)). Transgender women were also less likely to have received an HPV/PAP test compared with transgender men ($p\text{-value} < 0.0001$) or non-binary/genderqueer/another ($p\text{-value} < 0.0001$). Transgender men were more likely than non-binary/genderqueer/other to receive an HPV/PAP test ($p\text{-value} = 0.0031$). Individuals who began telling others they were transgender before the age of 18 were more likely to have received an HPV/PAP test compared to those who told others when they were 18 or older ($p\text{-value} = 0.0344$). Individuals who had a hysterectomy were more likely to have obtained an HPV/PAP test than individuals who did not have a hysterectomy ($p\text{-value} < 0.0001$) ([Table 2](#)). Among those who were assigned female at birth, 94.4% of those who had a hysterectomy had an HPV/PAP test versus 74.6% of those who did not have a hysterectomy. Among those assigned male at birth, 2 individuals reported having a hysterectomy, of which 1 reported having an HPV/PAP test (50.0%), and 13.2% of those who did not have a hysterectomy had an HPV/PAP test ([Table 8](#)). Of those who received a hysterectomy, 100.0% were undergoing GAHT and 90.0% received an HPV/PAP test ([Table 6](#)).

Table 2. Relationship between sex/gender identity predictors and screening adherence.

Characteristics	Mammography		No mammography		HPV/PAP test		no HPV/PAP test		PSA test		No PSA test		Colonoscopy		No colonoscopy		Overall ^a			
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%		
What sex were you assigned at birth (on your original birth certificate)?																				
Female	16	84.21%	3	15.79%	61	79.22%	16	20.78%	0	0.00%	11	100.00%	9	52.94%	8	47.06%	115	59.90%		
Male	13	34.21%	25	65.79%	10	14.29%	60	85.71%	3	18.75%	13	81.25%	14	48.28%	15	51.72%	77	40.10%	0.76	
Which of the following best describes your current gender identity (Please choose one)?																				
Woman/Transgender women/MTF	13	38.24%	21	61.76%	9	14.75%	52	85.25%	3	20.00%	12	80.00%	13	50.00%	13	50.00%	67	34.90%	0.837	
Man/Transgender man/FTM	12	85.71%	2	14.29%	40	85.11%	7	14.89%	0	0.00%	10	100.00%	7	46.67%	8	53.33%	71	36.98%	1*	
Non-binary/Genderqueer/Another	4	44.44%	5	55.56%	22	56.41%	17	43.59%	0	0.00%	2	100.00%	3	60.00%	2	40.00%	54	28.13%	1.00*	
At about what age did you begin to feel that your gender was different from your assigned birth sex?																				
< 18years old	25	49.02%	26	50.98%	65	48.51%	69	51.49%	3	12.50%	21	87.50%	17	44.74%	21	55.26%	168	87.50%	1*	
18years or older	4	66.67%	2	33.33%	6	46.15%	7	53.85%	0	0.00%	3	100.00%	6	75.00%	2	25.00%	24	12.50%	0.2427*	
At about what age did you start to think you were transgender (even if you did not know the word for it)?																				
< 18years old	21	55.26%	17	44.74%	56	53.33%	49	46.67%	2	10.00%	18	90.00%	14	46.67%	16	53.33%	130	67.71%	1*	
18years or older	8	42.11%	11	57.89%	15	35.71%	27	64.29%	1	14.29%	6	85.71%	9	56.25%	7	43.75%	62	32.29%	0.5358	
At about what age did you first start to tell others that you were transgender (even if you did not use that word)?																				
< 18years old	8	61.54%	5	38.46%	25	62.50%	15	37.50%	0	0.00%	8	100.00%	6	50.00%	6	50.00%	59	31.05%	0.5292*	
18years or older	21	48.84%	22	51.16%	45	42.86%	60	57.14%	3	16.67%	15	83.33%	17	51.52%	16	48.48%	131	68.95%	0.9284	

(Continued)

Table 2. Continued.

	Mammography		No mammography		HPV/PAP test		no HPV/PAP test		PSA test		No PSA test		Colonoscopy		No colonoscopy		Overall ^a	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Are you currently taking hormones for your gender identity or gender transition?																		
Yes	23	52.27%	21	47.73%	61	50.41%	60	49.59%	2	9.52%	19	90.48%	19	51.35%	18	48.65%	129	67.19%
No	6	46.15%	7	53.85%	10	38.46%	16	61.54%	1	16.67%	5	83.33%	4	44.44%	5	55.56%	63	32.81%
					p-value				p-value				p-value				p-value	
					0.6982				0.2685				0.5453*				1*	
Have you had top/chest surgery?																		
Yes	14	62.50%	8	37.50%	-	-	-	-	-	-	-	-	-	-	-	-	-	-
No	15	48.98%	20	51.02%	-	-	-	-	-	-	-	-	-	-	-	-	-	-
					p-value													
					0.1266													
Have you had a hysterectomy/hysto (removal of uterus, ovaries, fallopian tubes, and/or cervix)?																		
Yes	-	-	-	-	18	85.71%	2	14.29%	-	-	-	-	-	-	-	-	-	-
No	-	-	-	-	53	44.36%	74	55.64%	-	-	-	-	-	-	-	-	-	-
					p-value				<0.0001									

*Indicates use of Fisher's exact test.

^aOverall summary characteristics calculated using sample at baseline.

Three out of the 27 individuals eligible for prostate cancer screening received a PSA test (11.1%), while 23 out of the 46 individuals eligible for colorectal cancer screening received a colonoscopy (50.0%). No predictors were found to be associated with adherence to PSA testing or colonoscopy screening in our sample. Additionally, the socioeconomic factors we examined were not found to be significantly associated with cancer screening adherence (Table 4).

Discussion

Overall, our findings among the AFFIRM cohort indicate a lack of screening for breast, cervical, prostate and colon cancer in TGNB populations. Furthermore, several predictors related to gender identity and healthcare access were associated with cancer screening adherence.

The screening rates in AFFIRM are lower than national rates for cisgender men and women for mammographic (50.9% vs 69.1%) (FastStats, 2021), cervical (48.3% vs 82.9%) (Sabatino et al., 2021), prostate (11.1% vs 31.5%) (A New Study Finds Rates of Advanced Prostate Cancer Continued to Increase in Men Aged 50 and over after the USPSTF Recommended against PSA Screening for All Men, 2022) and colorectal (50% vs 60.6%) (CDCMMWR, 2020) screening. These adherence rates are based off age-dependent eligibility of the entire cohort and do not include sub-group analyses due to sample size limitations. We find similar trends between national and transgender populations when comparing Healthcare Effectiveness Data and Information Set (HEDIS) metrics. Amida Care is a private, nonprofit community health plan in New York City that specializes in serving Medicaid patients with chronic conditions that includes those who are living with HIV/AIDS and those who identify as TGNB (15%) (Who We Are | About Us | Amida Care | NYC Medicaid, n.d.). Compared to national reported HEDIS metrics for breast, cervical, and colorectal cancer screenings (HEDIS Measures and Technical Resources, n.d.), Amida Care – reported HEDIS screening rates were lower (Table 7). These metrics of the transgender populations from both the AFFIRM cohort and Amida Care compared to the national population demonstrate the lack of screening that

Table 3. Relationship between healthcare predictors and screening adherence.

Characteristics	Mammography		No mammography		p-value	HPV/PAP test		no HPV/PAP test		p-value	PSA test		No PSA test		p-value	Colonoscopy		No Colonoscopy		p-value	Overall ^a			
	n	%	n	%		n	%	n	%		n	%	n	%		n	%	n	%		n	%	N	%
Is there a place that you usually go to when you are sick or need advice about your health?																								
Yes	29	50.88%	28	49.12%	-	69	48.59%	73	51.41%	1*	3	11.11%	24	88.89%	-	23	50.00%	23	50.00%	0	0.00%	-	171	89.06%
No	0	0.00%	0	0.00%		2	40.00%	3	60.00%		0	0.00%	0	0.00%		0	0.00%	0	0.00%	0	0.00%		21	10.94%
Was there a time in the past 12 months when you needed to see a doctor but could not because of cost?																								
Yes	6	46.15%	7	53.85%	0.6982	22	47.83%	24	52.17%	0.9382	0	0.00%	6	100.00%	1*	5	55.56%	4	44.44%	1*	5	55.56%	44	22.92%
No	23	52.27%	21	47.73%		49	48.51%	52	51.49%		3	14.29%	18	85.71%		18	48.65%	19	51.35%		16	48.39%	148	77.08%
Do you have a doctor or health care provider who is knowledgeable about transgender health?																								
Yes	10	66.67%	5	33.33%	0.1541	30	50.85%	29	49.15%	0.6127	0	0.00%	8	100.00%	0.5323*	7	46.67%	8	53.33%	0.7531	7	46.67%	45	23.44%
No	19	45.24%	23	54.76%		41	46.59%	47	53.41%		3	15.79%	16	84.21%		16	51.61%	15	48.39%		16	51.61%	147	76.56%
What is your HIV status?																								
Positive	27	50.94%	26	49.06%	1*	64	48.12%	69	51.88%	0.8935	3	12.00%	22	88.00%	1*	22	51.16%	21	48.84%	1*	22	51.16%	146	76.44%
Negative	2	50.00%	2	50.00%		7	50.00%	7	50.00%		0	0.00%	2	100.00%		1	33.33%	2	66.67%		1	33.33%	45	23.56%
Overall summary characteristics calculated using sample at baseline.																								
What is your HIV status?																								
Positive	0	0.00%	7	100.00%	0.0045*	4	33.33%	8	66.67%	0.3141	0	0.00%	2	100.00%	1*	5	83.33%	1	16.67%	0.1868*	5	83.33%	13	7.14%
Negative	29	58.00%	21	42.00%		64	48.48%	68	51.52%		3	12.00%	22	88.00%		18	45.00%	22	55.00%		18	45.00%	169	92.86%

*Indicates use of Fisher's exact test.

^aOverall summary characteristics calculated using sample at baseline.

Table 4. Relationship between socioeconomic predictors and screening adherence.

Characteristics	Mammography		No mammography		HPV/PAP test		no HPV/PAP test		PSA test		No PSA test		Colonoscopy		No Colonoscopy		Overall ^b		
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	N	%	
Are you Hispanic/Latino/Latina?																			
Yes	4	44.44%	5	55.56%	13	40.63%	19	59.38%	0	0.00%	2	100.00%	4	66.67%	2	33.33%	43	22.40%	
No	25	52.08%	23	47.92%	58	50.43%	57	49.57%	3	12.00%	22	88.00%	19	47.50%	21	52.50%	149	77.60%	
What is your race? (Please check all that apply.)																			
White	22	59.46%	15	40.54%	47	52.22%	43	47.78%	3	15.79%	16	84.21%	15	50.00%	15	50.00%	1	119	61.98%
Other	7	35.00%	13	65.00%	24	42.11%	33	57.89%	0	0.00%	8	100.00%	8	50.00%	8	50.00%	73	38.02%	
Which of the following best describes your current employment status? (Please mark all that apply.)																			
Employed	17	44.74%	21	55.26%	61	50.41%	60	49.59%	2	16.67%	10	83.33%	14	46.67%	16	53.33%	133	69.27%	
Unemployed	12	63.16%	7	36.84%	10	38.46%	16	61.54%	1	6.67%	14	93.33%	9	56.25%	7	43.75%	59	30.73%	
What is your total annual personal income? Please only include the income you bring in from wages and salaries.																			
under \$24,000	14	58.33%	10	41.67%	36	48.65%	38	51.35%	2	13.33%	13	86.67%	11	52.38%	10	47.62%	103	54.21%	
\$24,000 and over	15	45.45%	18	54.55%	34	47.22%	38	52.78%	1	8.33%	11	91.67%	12	48.00%	13	52.00%	87	55.79%	
Where have you lived in the last 12 months? (Please mark all that apply.)																			
In stable housing	28	50.00%	28	50.00%	69	48.25%	74	51.75%	3	11.54%	23	88.46%	22	48.89%	23	51.11%	173	90.10%	
In unstable housing	1	100.00%	0	0.00%	2	50.00%	2	50.00%	0	0.00%	1	100.00%	1	100.00%	0	0.00%	19	9.90%	
You have difficulty finding housing or staying in housing.																			
Yes	15	51.72%	14	48.28%	43	47.78%	47	52.22%	0	0.00%	16	100.00%	15	62.50%	9	37.50%	78	40.63%	
No	14	50.00%	14	50.00%	28	49.12%	29	50.88%	3	27.27%	8	72.73%	8	36.36%	14	63.64%	114	59.37%	
You have difficulty finding employment or keeping employment, or have been denied promotion.																			
Yes	21	51.22%	20	48.78%	55	47.83%	60	52.17%	2	10.00%	18	90.00%	17	48.57%	18	51.43%	121	63.35%	
No	8	50.00%	8	50.00%	16	50.00%	16	50.00%	1	14.29%	6	85.71%	6	54.55%	5	45.45%	70	36.65%	

*Indicates use of Fisher's exact test.

^bOverall summary characteristics calculated using sample at baseline.

Table 5. Relationship between hormone use and screening adherence stratified by sex assigned at birth.

Screening type	Assigned male at birth		Assigned female at birth	
	No hormones	Hormones	No hormones	Hormones
Mammogram				
No	7 (77.78%)	18 (62.07%)	0 (0.00%)	3 (20.00%)
Yes	2 (22.22%)	11 (37.93%)	4 (100%)	12 (80.00%)
HPV/PAP test				
No	11 (91.67%)	49 (84.48%)	5 (35.71%)	11 (17.46%)
Yes	1 (8.33%)	9 (15.52%)	9 (64.29%)	52 (82.54%)
PSA test				
No	4 (80.00%)	9 (81.82%)	1 (100.00%)	10 (100.00%)
Yes	1 (20.00%)	2 (18.18%)	0 (0.00%)	0 (0.00%)
Colonoscopy				
No	5 (71.43%)	10 (45.45%)	0 (0.00%)	8 (53.55%)
Yes	2 (28.57%)	12 (54.55%)	2 (100.00%)	7 (46.67%)

Table 6. Relationship between hormone use and screening adherence stratified by gender affirming surgery.

Screening type	No gender affirming surgery		Gender affirming surgery	
	No hormones	Hormones	No hormones	Hormones
Mammogram				
No	6 (66.66%)	14 (53.85%)	1 (25.00%)	7 (38.89%)
Yes	3 (33.33%)	12 (46.15%)	3 (75.00%)	11 (61.11%)
HPV/PAP test				
No	16 (61.54%)	58 (57.43%)	0 (0.00%)	2 (10.00%)
Yes	10 (38.46%)	43 (42.57%)	0 (0.00%)	18 (90.00%)

*Analyzed top surgery and hysterectomy, respectively

Table 7. Screening rates.

	Breast	Cervical	Prostate	Colorectal
AFFIRM study				
% (n)	50.9 (29)	48.3 (71)	11.1 (3)	50.0 (23)
HEDIS reported				
%				
AmidaCare	43.8	42.6	–	55.6
Medicare HMO	69.4	–	–	69.8
Medicaid HMO	53.7	56.8	–	–

Table 8. Relationship between gender affirming surgery and screening adherence stratified by sex assigned at birth.

Screening type	Assigned male at birth		Assigned female at birth	
	No gender affirming surgery	Gender affirming surgery	No gender affirming surgery	Gender affirming surgery
Mammogram				
No	20 (66.67%)	5 (62.50%)	0 (0.00%)	3 (21.43%)
Yes	10 (33.33%)	3 (37.50%)	5 (100.00%)	11 (78.57%)
HPV/PAP test				
No	59 (86.76%)	1 (50.00%)	15 (25.42%)	1 (5.56%)
Yes	9 (13.24%)	1 (50.00%)	44 (74.58%)	17 (94.44%)

*Analyzed top surgery and hysterectomy, respectively.

transgender individuals undergo for breast, cervical, prostate, and colorectal cancers, and even more so for those living with HIV. Our results are also consistent with other recent studies which found less than 50% of the transgender and non-binary samples in Milwaukee and Chicago had

undergone screening (Luehmann et al., 2022; Roznovjak et al., 2023). On the other hand, a nationally representative sample from the 2014 Behavioral Risk Factor Surveillance System survey found screening rates in their transgender and nonbinary sample to be higher at 60–75% and more comparable to the cisgender sample (Narayan et al., 2017). The inconsistency among studies may point to specific subgroups of the TGNB population who are under screened, such as those living with HIV.

TGNB tended to follow the screening guidelines of their sex assigned at birth. Transgender men were more likely than transgender women to obtain a mammogram and HPV/PAP test. This held true when comparing mammography rates of those assigned male at birth and assigned female at birth stratified by gender affirming surgery (Table 8), which is inconsistent with what is currently recommended for transgender men as those with top surgery are recommended to get clinical chest exams and not mammography. Furthermore, one might expect screening rates to be higher in transgender women because guidelines recommend those who are at least 50 years old and taking hormones for more than 5 years, should receive mammograms every 2 years. Future guidelines should consider the role of gender-affirming hormones for both transgender men and women since studies with cisgender women implicate various formulations of exogenous hormones with increased risk breast cancer (Blok et al., 2019). In addition, we found that 14.7% of transgender women who were above the age of 21 received an HPV/PAP test. While there are currently no official guidelines offering recommendations of screening for transgender women who had bottom surgery to create a neo-cervix, the Canadian Cancer Society states there is a small risk of cancer developing in the tissues of the neo-cervix (Lee, 2021), suggesting further research needs to be done to create guidelines to address the unique risks this population faces.

Some organizing bodies advocate “screen now, screen regularly, and screen what you have” (Nikolić et al., 2018), indicating that screening should be based on an inventory of organs rather than gender identity. The organ driven approach

should consider minimizing body dysphoria or discomfort that TGNB individuals may experience during these physical examinations through gender-affirming care. For instance, one factor that leads to underscreening of cervical cancer in transgender men is the frequency of inadequate pap smears. Pap smears collected from transgender men have ten-fold higher odds of receiving an inadequate sample compared to cisgender women. After receiving an inadequate pap smear, transgender men patients took 5 times longer to return for retesting than cisgender women. Inadequate samples are likely due to both provider/patient discomfort when administering the exam as well as physical changes as a result of testosterone therapy (Peitzmeier et al., 2014) that lead to vulvovaginal changes due to estrogen deficiency. Inadequate pap smear frequency is positively correlated to the amount of time spent on testosterone therapy (*Screening for Cervical Cancer in Transgender Men | Gender Affirming Health Program*, n.d.). Gender-affirming care could include a treatment prior to pap testing to reduce risk of inadequate pap smears among transgender men. Unsatisfactory or inadequate pap smears results in samples that are unable to be evaluated by a laboratory and are of clinical significance because evidence has shown that cisgender women with previous inadequate pap tests are at risk of developing high-grade lesions (Bofin et al., 2007; Hock et al., 2003).

Individuals who began telling others they were transgender at a younger age (< 18) were more likely to receive HPV/PAP screening than those who began telling others at an older age (18 or older). Gender dysphoria can begin during early childhood, and many years can elapse before an individual chooses to commence gender transition (Zaliznyak et al., 2021). This can impact whether these patients are interacting with providers who are knowledgeable about transgender care and can address the needs of this patient population. Individuals who obtained a hysterectomy were also more likely to have had an HPV/PAP test, further supporting that contact with the healthcare system for gender affirming care can increase uptake of other healthcare needs such as cancer screenings.

While our results did not identify any specific socioeconomic barriers to cancer screening, it is known that various factors such as housing and employment insecurity can prevent TGNB individuals from accessing gender-competent healthcare (Safer et al., 2016). We found that individuals who are HIV positive were less likely to receive a mammogram than those who were HIV negative. TGNB individuals are disproportionately burdened by HIV (Stutterheim et al., 2021), and people living with HIV are at increased risk for many cancers (*HIV and Cancer | American Cancer Society*, n.d.), amplifying the need for adequate screening in this population. Underscreening among TGNB with HIV in this study could also be due to socioeconomic barriers, as HIV disproportionately affects those of lower socioeconomic status (Pellowski et al., 2013) which can impact access to health care services.

The strengths of this study were that a large variety of predictors specific to TGNB were included, including gender identity questions. In addition, the entire sample population was fully TGNB with individuals spanning different geographic locations throughout the country. This study does have a number of limitations. First, we were not able to establish temporality as our cancer screening questions were only available in the last wave of the study. Second, this study is subject to the expected limitations of observational design, with self-report. Third, a limitation to the analysis was the smaller sample size overall and for each screening type, as only individuals who met the current age criteria for screening were included in the final analysis. Additionally, we did not have details on family/personal history of cancer nor frequency of screening.

Conclusion

Overall, the results of this study conclude that the TGNB population lacks adequate screening. Future efforts to mitigate the barriers to screening adherence should be targeted at the healthcare system level. Furthermore, more evidence is needed to tailor cancer screening guidelines for TGNB and take into account the unique risks which may be higher or lower than cisgender counterparts.

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Disclosure statement

The authors declare no potential conflicts of interest.

Statement of significance

There are limited evidence-based, tailored cancer screening guidelines for transgender individuals. The present study seeks to identify patterns associated with screening adherence among transgender individuals to inform efforts to mitigate screening barriers.

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