HPV Cancers Alliance
Spread Knowledge. Save Lives.

The Conversation Case

An HPV-Focused Toolkit for Gastroenterology Providers: Advancing Prevention, Detection & Dialogue in Clinical Practice

HPV doesn't discriminate. It affects people of all genders and sexual orientations, and its transmission isn't limited to any one behavior.

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Stigma and misinformation around HPV creates barriers to vaccination, screening, and treatment. As providers, we are critical in correcting misconceptions and emphasizing that HPV infection and related cancers are clinical issues. Clear, evidence-based communication empowers patients to take action without fear or shame.

"We need to overcome these significant challenges (screening, awareness, etc.) to ensure effective implementation of screening for equitable cancer prevention and reducing disparities."

– Ashish A. Deshmukh, PH.D., MPH, Associate Professor, Department of Public Health Sciences, Medical University of South Carolina

Section 1: Facts & Figures

What is HPV (Human Papillomavirus)?

Human papillomavirus (HPV) is a group of more than 200 related viruses, with over 40 types transmitted through sexual contact. HPV can infect the skin and mucous membranes, leading to conditions ranging from benign warts to various cancers.[1]

Prevalence – Widespread & Misunderstood

HPV is the most common sexually transmitted infection worldwide. It's estimated that more than 80% of women and men acquire HPV by the age of 45.[2]

Asymptomatic Nature – The Silent Infection

The majority of HPV infections are asymptomatic and resolve spontaneously. Approximately 90% of individuals clear the virus within two years. However, about 10% of infections persist, increasing the risk of these individuals developing cancers.[3]

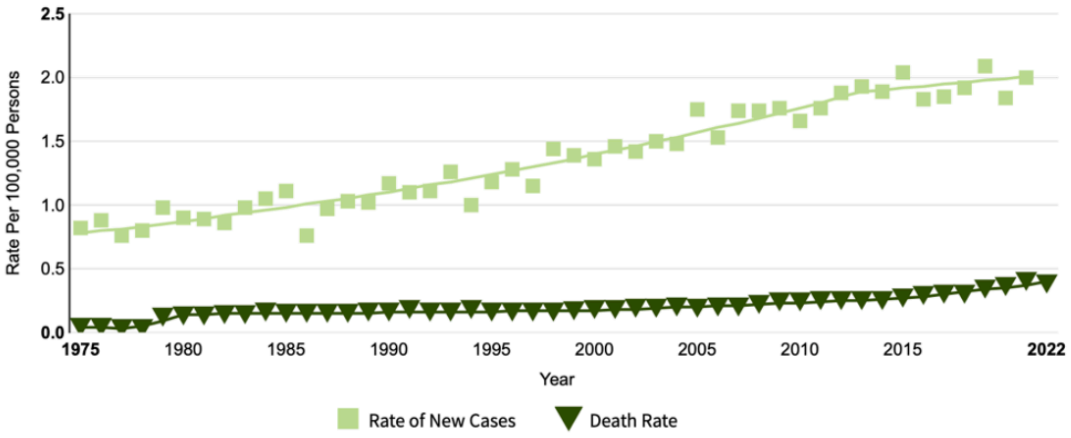
Cancer Association – The Link to Disease Prevention

Persistent infection with high-risk HPV types is a significant cause of various cancers, including cervical, anal, and oropharyngeal cancers. HPV is linked to nearly 5% of all cancers worldwide.[3]

GI Cancers Caused by HPV Infection

Anal cancer is the most common HPV-related gastrointestinal (GI) cancer. Although HPV has been linked to other GI cancers, its causal role is less well established. According to the NIH's National Cancer Institute, HPV infection is found in 90% of anal cancer cases, with HPV16 & HPV18 being the most common causative types.[1]

Anal Cancer Incidence is Actively Increasing, with ~10,540 New Cases in 2024



New cases come from Surveillance, Epidemiology and End Results Program (NCI SEER) 8. Deaths come from U.S. Mortality. All Races, Both Sexes. Rates are Age-Adjusted.[4]

Other Cancers

Emerging research suggests a potential link between HPV infection and esophageal or gastric cancer, though further studies are needed to confirm and clarify this association.[5–6]

Symptoms Caused by HPV infection

HPV infections often do not cause symptoms. Most individuals with HPV are unaware of their infection unless it is detected through routine screening or if they develop symptoms. Approximately 90% of HPV infections resolve on their own within two years without causing health problems.[7]

However, certain strains of HPV can lead to visible symptoms, such as:

Genital Warts: Caused by HPV types 6 and 11, these are painless growths on the genitals, anus, or in the throat.
Recurrent Respiratory Papillomatosis: Also linked to HPV 6 and 11, this condition causes wart–like growths in the airways, leading to breathing difficulties.

HPV Vaccine: Preventing HPV Infection

The HPV vaccine is a highly effective preventive measure against HPV–related cancers and genital warts. Clinical trials have demonstrated that the vaccine is more than 98% effective in developing an antibody response to the HPV types included in the vaccine one month after completing the full vaccination series.[8]

Vaccination is most effective when administered before individuals become sexually active, as it provides protection prior to potential exposure to the virus.[9] The vaccine is recommended for:

Adolescents: Ages 9–14, with a two–dose schedule.
Adolescents and Young Adults: Ages 15–26, with a three–dose schedule.

Recent studies indicate that initiating vaccination at younger ages (9–14 years) results in higher vaccine effectiveness, ranging from approximately 74% to 93%.[9]

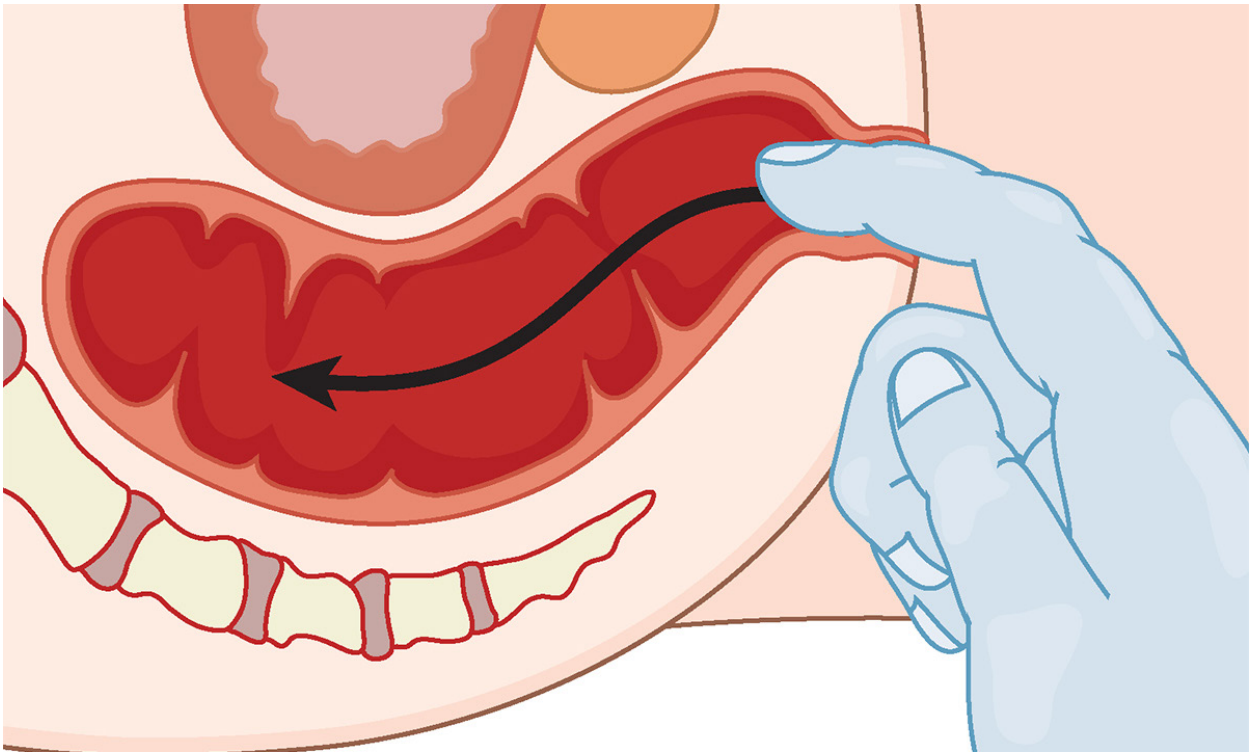
Research shows that the use of the digital anorectal exam **(DARE)** has declined over time, with some healthcare providers either underutilizing the procedure or applying it inconsistently. In the following sections, we delve into the reasons behind this trend, highlighting the benefits and importance of DARE despite the lack of comprehensive guidelines.

Terminology Use in This Toolkit: DRE vs. DARE

This toolkit references both digital rectal examination (DRE) and digital anorectal examination (DARE). DRE is a basic procedure that involves a clinician manually examining the rectum for abnormalities. This procedure is commonly used for routine rectal cancer screenings but is not comprehensive for detecting anal cancer.

DARE, which includes DRE, is meant to detect lumps in the anus or around the anus that may indicate the presence of anal cancer. It represents a more comprehensive approach to screening, particularly for high-risk populations like individuals with HIV, men who have sex with men (MSM), and immunocompromised patients.

Anal cancer prevention is also very important in these populations. While DARE is a tool to detect an anal cancer that is already there, other tests are needed to detect changes in the anal lining that are precancerous, and which could progress over time to cancer if left untreated. These include anal swabs for cytology or HPV testing, and high resolution anoscopy (HRA) with biopsy of abnormal-looking tissues. In sum: DARE for anal cancer detection and HRA for anal cancer prevention among those who do not have anal cancer.



Section 2: Issue Statement

Expanding the use of DRE/DARE beyond traditionally high-risk groups can help bridge gaps in early detection and improve anal cancer screening/ prevention efforts.

Critically Addressing Stigma & Misinformation

There is a persistent stigma surrounding HPV, particularly when it comes to anal cancer. Some healthcare providers, including gastroenterologists, may incorrectly associate anal cancer solely with a history of anal intercourse, overlooking other risk factors contributing to disease development. However, this thinking is incorrect – not everyone diagnosed with anal cancer has had anal intercourse, and HPV can infect various mucous membranes of the body, including those in the cervix, anus, throat, and genitals, regardless of specific sexual behaviors.

Transmission Modes – Shifting Our Focus Beyond Sexual Behavior

HPV is not a typical STI; it is the most common STI worldwide. HPV is primarily transmitted through sexual contact including vaginal, anal, and oral sex. It's important to understand that HPV transmission is not limited to penetrative sex. The virus spreads through intimate skin–to–skin contact and is not exclusively linked to any one type of sexual activity. It can also spread from one body site to another body site in the same person.[10]

Despite its clear link to anogenital and oropharyngeal cancers, HPV is often overlooked in GI care. Many patients at highest risk for HPV–related cancers are regularly seen by gastroenterology providers. Yet, opportunities to address HPV risk, promote vaccination and screening to support prevention of anal cancer, and early detection of existing anal cancer, are still being missed.[11]

"It is the provider's responsibility to bridge the inherent physician–patient power gradient by creating an equitable clinical environment in which patients feel empowered and informed about their care." [11]

Supporting Facts

Increased Need for DRE/DARE Utilization

- In 2020, a comprehensive national analysis of anal cancer trends was conducted for the first time, uncovering a significant increase in the incidence of HPV–associated squamous cell carcinoma (SCCA) – the most common histologic subtype of anal cancer – along with a rise in advanced–stage cases and mortality rates.[12]

- Anal cancer incidence and mortality rates have increased 1.5–fold in both men and women over 50 – and more than two–fold in men and women living in Midwestern and Southeastern states.[12]

- Anal cancer is now more common than cervical cancer among some populations, specifically white women over the age of 65.[13]

- The American Cancer Society (ACS) predicts more than 10,000 new cases in the U.S. in 2024 alone.[14] Research on future patterns in burden and incidence of anal cancer, most notably among high–risk groups, states this trend will continue, with a significant impact on the healthcare system due to the aging population.[15]

- Implementing routine DRE/DAREs and anal cancer screening can play a pivotal role in mitigating the rising incidence of anal cancer. DARE is a simple, safe, and widely accessible procedure that facilitates early detection of anal cancers, enabling timely intervention and reducing the likelihood of progression to advanced–stage disease.[16–17]

THOUGHTS FROM THE FIELD:
Insights from Leading Experts in Gastroenterology

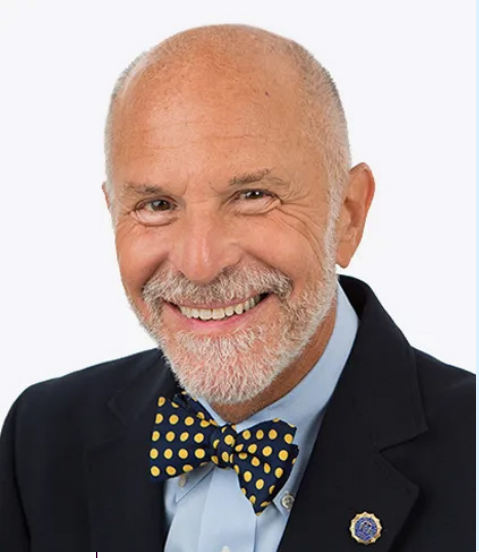
Joel Palefsky, M.D., C.M., F.R.C.P.(C). Director, Anal Neoplasia Clinic, Research & Education Center Infectious disease physician at University of California San Francisco

Internationally recognized researcher, leader of the ANCHOR Study, and founder of the International Anal Neoplasia Society

"Most cases of anal cancer are diagnosed in people who are not in any of the high risk groups. We should emphasize the 'A' in DARE; It's hard to pick up subtle precancerous regions, and we need to be more sensitized to this. Generational differences and varying task force guidelines create challenges. So, if we don't approach this correctly, these precancerous conditions won't be found. Let's connect the dots and build clinician-based awareness. When the guidelines aren't consistent, it's usually because they are wrong."

Carl McDougall, M.D. Associate Attending Physician, Gastroenterologist at The New York Hospital & Associate Clinical Professor of Medicine at Weill Medical College

"Anal cancer is often viewed as an outlier, but projections are certainly likely to change. There's a latency between HPV infection and cancer development that we need to keep in mind. Procedures like the DARE are important, though visits are often symptom-motivated, with only a fraction related to HPV or anal cancer. The common narrative is that anal cancer symptoms are often mistaken for hemorrhoids. Younger trainees are less likely to perform visual exams and DAREs before a colonoscopy, but it's the routine rectal exam that truly makes the difference."



Lawrence Brandt, M.D. Professor, Department of Medicine (Gastroenterology) & Department of Surgery at Albert Einstein College of Medicine

"The decline in proper DAREs can be traced to societal taboos and the decrease in experienced practitioners as seasoned doctors retire. Many providers don't know how to perform the procedure or question its necessity when a colonoscope is used. As a result, proper DAREs are often not performed, and providers need to take responsibility for this. There's also a lack of history being taken, intimacy issues, and discomfort between provider and patient. These challenges often tie into difficult socio-sexual questions, such as asking about sexual preference and partners."

Evolving the Role of DARE: A Call for Reflection and Action

Is there room to expand the guidelines? We think so. Despite the well-documented risk of anal cancer in high-risk populations, screening remains inconsistent and opportunities for early detection are often missed. The International Anal Neoplasia Society (IANS) recommended procedures for identifying abnormalities in the anal canal, perianal region, and distal rectum, including anal cancer and precancerous lesions:

Sensitivity and Specificity: Studies indicate that DARE detects lesions as small as 3 mm, with sensitivity between 71%–80% and specificity between 92%–100%.[18]

Targeted Screening: Current guidelines prioritize DARE for high-risk populations (HIV-positive individuals and MSM) due to their elevated risk of HPV-associated anal cancer.[16,18–19]

Follow-Up Matters: Abnormal findings necessitate further evaluation through tissue sampling and High-Resolution Anoscopy when appropriate.

Bridging the Gap in Practice: Despite its strong endorsement, DARE remains underutilized, often omitted from routine screening protocols.[16,19]

A Practical, Accessible Tool: DARE is minimally invasive, cost-effective, well-accepted by patients, and has a low risk of adverse effects.[16,18–19]
Training and Clinical Judgment: Proper training is essential to ensure accurate detection and appropriate follow-up.[16,18–19]

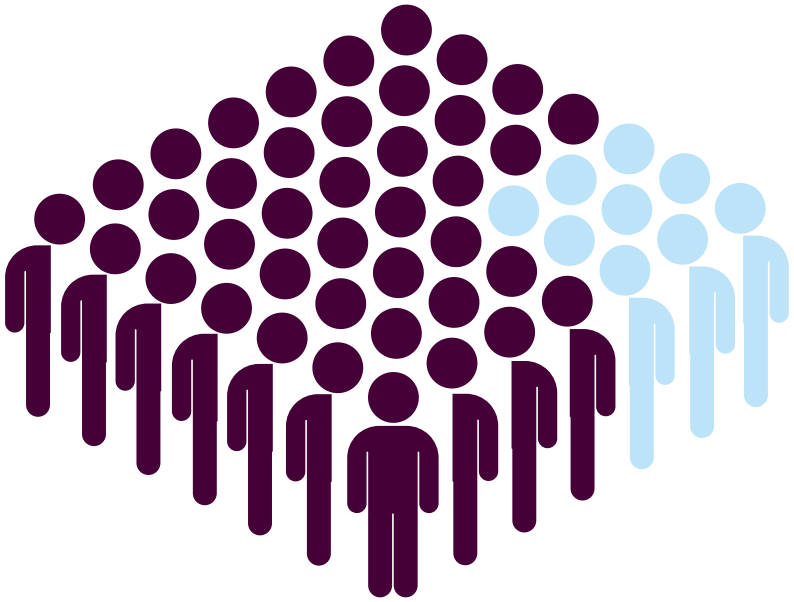
The Next Step: Moving Beyond High-Risk Populations

"The mildly invasive nature of DARE, limited likelihood of adverse procedure-related events, cost-effectiveness and patient acceptability, as well as wide availability" support consideration of its integration into screening programs.[11]

While the IANS guidelines provide a strong foundation, we must ask ourselves: How do we expand the reach of these screenings to the broader population at risk? Should DARE be more widely integrated into routine exams, particularly for individuals with other risk factors such as a history of HPV-related disease, immunosuppression, or persistent anal symptoms?

This toolkit is designed to help clinicians incorporate DARE into their practice effectively, addressing both the high-risk groups outlined in the guidelines and the larger population who may benefit from early detection. By critically evaluating our current practices, we can evolve these guidelines into a more comprehensive,

standardized approach to anal cancer prevention.
The challenge is clear. The tools are in place. The next step is in our hands.



Missed Anal Cancer Diagnoses

vs.

Proactive Detection of Precancerous & Cancerous Lesions

Expanding Anal Cancer Screening

Hesitancy to Perform DRE/DAREs

Generational differences in medical training and practice have contributed to a decline in the routine use of DRE/DAREs.

Studies suggest that younger gastroenterologists are less likely to perform DREs as part of routine anal cancer screening, often relying more on colonoscopy for diagnosis. This gap may stem from limited formal education on the procedure, misconceptions about its effectiveness compared to other diagnostic tools, or personal discomfort.[11,19]

To bridge this divide, it is essential to unify our approach across generations and reaffirm the clinical value of DRE/DAREs. When used correctly alongside other screening tools, the DRE improves early detection rates and enhances patient outcomes.

Where Do You Fall?

Younger Gastroenterologists: What's holding you back from performing DAREs regularly?

Older Gastroenterologists: How can you guide the next generation to integrate this critical skill into their practice?

Equipping gastroenterologists with the necessary training, resources, and support is key to overcoming hesitancy and reinforcing DARE as a vital part of routine screening. What do you need to feel more confident in performing DAREs?

A Message from Lillian Kreppel: The Missed Diagnosis That Changed My Life

I'm not a doctor, but I'm here today because of one, and because I didn't give up on myself when I knew something was wrong. I'm also here because I want to make sure the cancer I had doesn't get missed. I was diagnosed with stage II anal cancer in 2017. I had been experiencing strange symptoms like rectal bleeding, pressure, discomfort, even during Pilates classes. It didn't feel "serious" at first, but something in me knew it wasn't normal.

When I first brought up these symptoms to a doctor, it wasn't taken seriously. I had to keep pushing. I went from one office to another, navigating uncomfortable conversations, stigma, and vague answers. A colonoscopy found hemorrhoids, but I knew that wasn't the full picture. Eventually, a proper exam by my gastroenterologist and a sigmoisocopy confirmed a diagnosis of anal cancer.

No one told me this was something I should be screened for. I knew I had HPV, but not this risk. I wasn't immunocompromised, I didn't fit the "profile", and yet, there I was, receiving a cancer diagnosis for a disease that is increasing in incidence but still hugely under-discussed in GI and primary care spaces. After 28 days of radiation treatment, combined with daily oral chemotherapy, and the emotional toll of confronting a disease that no one around me was talking about, I survived. I decided that silence wasn't going to be the final chapter.

I co-founded the HPV Cancers Alliance to spread knowledge and save lives by educating, destigmatizing, and mobilizing providers like you to be proactive in talking about HPV and anal cancer – not only with high-risk patients, but with everyone. Don't wait for a patient to ask about HPV and normalize screening for nal cancer. Behind every missed diagnosis is someone like me, someone who just needed one doctor to connect the dots.

Thank you for being that doctor for someone else.

Section 4: Actionable Items for GI Audience

Glossary

HPV Screening & Risk Assessment Questions for Office Intake Form

HPV Vaccination

1. Have you ever received the HPV vaccine? (YES) (NO)
2. If yes, have you completed the HPV vaccination series (two doses between ages 9–14 OR three doses between ages 15–26) ? (YES) (NO)

HPV Screening

1. Have you ever undergone screening for HPV-related diseases (e.g., anal Pap test, cervical Pap smear test, HPV DNA testing)? (YES) (NO)
2. If yes, when was your most recent screening? _____
3. Have you ever been advised to have more frequent screenings due to HPV or related abnormalities?

HPV History

1. Have you ever been diagnosed with any HPV-related conditions (e.g., genital warts, anal dysplasia, cervical dysplasia, or anal cancer)? (YES) (NO)
2. If yes, please specify the condition and approximate date of diagnosis: _____ _____
3. Are you currently experiencing any symptoms such as anal pain, bleeding, or unusual discharge? (YES) (NO)

1. Clarifying HPV Symptoms and Raising Clinical Suspicion

Key Message: Most high-risk HPV infections cause no symptoms, but the outcomes can be serious if left unchecked.

Talking Points:

- "HPV itself often has no signs or symptoms, especially the high-risk types that can lead to cancer."
- "That's why we pay close attention to persistent symptoms that could indicate early changes, even if they seem minor."
- "Not everything that bleeds is a hemorrhoid. Persistent bleeding, pain, or itching in the anal or rectal area requires a closer look."
- "By doing this work early, we often catch problems before they become something more serious."

Common Warning Signs to Watch For:

- Rectal or anal bleeding (especially if persistent or unexplained)
- Anal pain, itching, or pressure
- Lumps or growths near the anus
- Changes in bowel habits

2. Addressing Patient Hesitancy Around Digital Anorectal Examination (DARE)

Key Message: We understand this can feel uncomfortable, but it's a quick, routine part of care, and a effective tool in protecting your long-term health."

Talking Points:

- "It's completely normal to feel a bit uneasy about a rectal exam, and I'm here to make this as comfortable as possible for you."
- "The exam only takes a minute or two, but it gives us vital information that could detect problems early, when they're most treatable."
- "I'll walk you through everything as we go. If at any point you feel uncomfortable, we can pause."

Tips for Providers:

- Normalize the procedure as standard, routine, and brief
- Provide context: "This is part of cancer prevention, not because we expect something is wrong."
- Offer privacy, reassurance, and simple language

3. Explaining HPV Status and Anal Cancer Risk

Key Message: HPV is common, but for some people, it can increase the risk of cancer. That's why we screen and stay proactive.

Talking Points:

- "Most people will have HPV at some point in their lives, it's very common and usually goes away on its own."
- "However, certain high-risk types of HPV can cause changes in cells that may lead to cancer over time if not monitored."
- "If you've tested positive for high-risk HPV, it doesn't mean you have cancer. It just means we'll keep a closer eye on things to protect your health."
- "Anal cancer is rare, but it's becoming more common. That's why we want to be thorough and catch any changes early."

Risk Factors Worth Highlighting:

- History of receptive anal sex
- HIV or immunosuppression
- Smoking
- History of genital warts or HPV-related dysplasia/cancers
- Previous abnormal cervical or anal screening

“It’s OK to Ask Me About HPV.”

Let’s talk openly–
for your health.

What You Might Not Know:

- HPV can affect everyone regardless of gender, age, or orientation.
- Some strains of HPV are linked to anal cancer.
- Symptoms like rectal bleeding, itching, or pain? Not everything that bleeds is a hemorrhoid.
- Talking about HPV helps us catch changes early, before they become serious.

Start the conversation with your GI provider today.

Your questions matter.
Your voice matters.
Early awareness saves lives.

HPV Cancers Alliance
Spread Knowledge. Save Lives.

Brought to you by HPV Cancers Alliance
Learn more: www.hpvca.org | IG: @hpvcancersalliance

Knowledge is Power....
The Power to Prevent Cancer

Most people have been exposed to the HPV virus without experiencing symptoms. If you are one of the many, it's important to know what type you may have. ***WHY?***

1. Your Type Can Determine Your Plan
The High-risk types of HPV can cause cervical cancer and lead to other cancers such as anal, vaginal, vulvar, penile and throat cancers. The sooner you know your status, the more you can do to prevent
these cancers.

2. Your Plan Can Help You Prevent Cancers
If you should test positive for high risk HPV, your doctor may recommend more frequent screening or follow-up procedures. The point is you have options.

3. Your Awareness of Your Status Can Help You Navigate Sensitive Situations
If you test negative for high-risk HPV, you have the reassurance you need to continue your regular screening plans and to communicate openly with your partner about your status.

If you test positive for high-risk HPV, you will have the knowledge you need to move from **WHAT IF?** To **WHAT NOW?**

Ask your provider about getting tested for HPV. Know your status, know your options.

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