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Mollie E. Alleshire, DNP, MSN, Brad Belnap, Keisa L. Bennett, MD, MPH, Richard Burns, Anthony R. Campo, MA, BA, Robert Crane, MD, Kristen Emory, PhD, Amanda Fallin-Bennett, PhD, RN, Naomi Goldberg, Larry Kairaiuak, Elizabeth Kind, Gil Lorenzo, Amy Lukowski, Psy.D, Ana Maria Machado, MPH, Jamie Magee, Archana Maini, MD, Loui Marven, Michelle A Marzullo, PhD, MA, BA, Jennifer Matekuare, Eliza Muse, Shor Salkas, MPH, AsherLev Santos, PhD, MPIA, Catherine Saucedo, Adrian Shanker, Donna Solomon-Carter, Julia Thorsness, Regina Washington, DrPH, and Jenna Wintemberg.

The following individuals have disclosed a relevant financial interest/arrangement or affiliation with a commercial interest who provides products or services relating to their presentation(s) in the continuing education activity. All conflicts of interest have been resolved in accordance with the ACCME Standards for Commercial Support:

Sheryl Zayas, DO - Gilead
Best Practices for Cervical Cancer Screening Among LBTQ Individuals

Amanda Fallin-Bennett, PhD, RN
Assistant Professor
Persistent HPV infection is the most common cause of cervical cancer.
Cervical Cancer

~ Detectable ~
A pap smear is a preventative screening test for cervical cancer.

~ Preventable ~
The Gardasil vaccine protects against HPV, the main cause of cervical cancer.

~ Treatable ~
When caught in the early stages, you have an 80% chance of beating the cancer. This is why it's so important to keep up with your annual exams.

FpaWomenshealth.com
No woman should die of cervical cancer
Screening leads to fewer deaths

We can do better.

SOURCE: National Cancer Institute, 2014
Why is cervical cancer an LBTQ issue?

- Lower rates of HPV vaccine
- Higher rates of smoking
- Lower rates of screening
Of note…

• The majority of lesbian identified women have a lifetime history of sex with men
• Transmission of HPV between female partners is possible
• Sexual minority adolescents report riskier sexual behavior and earlier age of first intercourse
How can we reduce cervical cancer risk?
Lesbian and bisexual young adults were 72% more likely to receive the HPV vaccine when they perceived a positive social norm among their peers.
There are strong, trusted LBT community organizations that can be engaged to promote health.
Train culturally competent health care providers!
• 50% of providers at academic medical centers report having received no training on LGBT health issues
• Only 4% of academic medical centers have a process for identifying LGBT friendly providers
• Some LBT patients report avoiding healthcare system due to fear of discrimination
  • 28% of FTM report not finding transgender-sensitive gynecological care
  • 50% report needing to educate their provider on their health needs
Everyone with a cervix is at risk for cervical cancer!
Create a welcoming office environment

PATIENT RIGHTS

1. Consistent and respectful care, to be made comfortable.
   You have the right to receive care from your therapist, psychologist, spiritual, and personal values, beliefs, and preferences.

2. To have a family member or other representative of your choosing and your own physician located nearby to provide adequate care.

3. To be informed of the name of the physician who will be responsible for your care and the names and professional relationships of other physicians and non-physicians who will be involved.

4. To receive information about your health status, diagnosis, prognosis, course of treatment, progress, and any complications of your condition that arise in the course of your care, including issues of confidentiality, withholding or withdrawing life-sustaining treatment.

5. To make decisions regarding medical care, and receive in a timely manner information about any proposed treatment or procedure as you may want to make informed decisions or refuse a course of treatment. Except in emergencies, this information shall include: the diagnosis of the condition, the condition and the risks involved in such, the name of the person who will carry out the procedure or treatment.

6. To receive all information and consultation as to the course of treatment and the risks involved in such, the name of the person who will carry out the procedure or treatment.

7. To request or refuse treatment, to the extent permitted by law.
   However, you do not have the right to demand inappropriate or medically unnecessary treatment or services. You have the right to give the named representative the actual contact information for the hospital.

8. To be advised if the hospital/personal physician proposes to concur or to obtain necessary information to make your own or your representative's decisions.

9. To be informed if the hospital/personal physician proposes to concur or to obtain necessary information to make your own or your representative's decisions.

10. To be advised if the hospital/personal physician proposes to concur or to obtain necessary information to make your own or your representative's decisions.

11. To receive care in a safe setting, free from emotional, physical, sexual, or verbal abuse and neglect, intimidation or harassment. You have the right to access protective and advocacy services including seeking enforcement of a restraining or abuse.

12. To be free from restraint and seclusion at any time used as a means of coercion, discipline, convenience or retaliation by medical staff.

13. To be informed of your rights and have the right to advance the time and manner of appointments as well as the identity of all persons providing the care.

14. To be informed by the physician or a delegate of the physician, of continuing right to review and to challenge the denial of reimbursement to any person enrolled in your Medicare, Medicaid, or any other insurance benefit program including the development and implementation of your discharge plan. Upon request, a brother, sister, family member may be provided with this information.

15. To know which hospital rules and policies apply to your conduct while a patient.

16. To designate visitors of your choice. If you have designated visitors making agency, whether or not the visitation is limited by law or regulations.

17. To make requests of the hospital, including reasonable restrictions on contact with your visiting family and friends.

18. To receive or refuse the services of any person or organization that affects your care.

19. To be advised of the hospital's policies and procedures, including rights and responsibilities.

20. To receive and be ensured the hospital's policy on the release of information to anyone including the release of information to any person designated to you by the patient.

21. To make requests of the hospital, including reasonable restrictions on contact with your visiting family and friends.

22. To file a grievance. If you wish to file a grievance with this hospital, you may do so by writing or calling.

Pregunta y dígalo:
Hable con su proveedor de atención médica sobre ser LGBT

You have the right to:

1. Consistent and respectful care, to be made comfortable.
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Create a welcoming office environment
Create a welcoming office environment

---

**Preferred name. Specify:**

---

**Preferred gender pronouns:**

- [ ] He/Him
- [ ] She/Her
- [ ] They/Them
- [ ] Other__________________________
Take an Inclusive History

• Avoid assumptions
• Avoid value statements
• Ask specifics
• Use gender neutral terms
• Avoid labeling sexual practices
• Ask the patient how they identify
• Ask to clarify if you are unsure
Cervical Cancer Screening Tips for Women who have Sex with Women

- Take an inclusive sexual history
- Be sensitive to discomfort with the exam
- As with all patients...
  - Approach patients in a sensitive manner
  - Use the smallest speculum necessary
  - Honor reports of discomfort
  - Consider bimanual exam first to assess pelvic landmarks
Cervical Cancer for Screening Tips Trans* Men

- May have particular difficulty with the exam
- Use extra sensitivity with terminology comfortable to patient
- Be as efficient as possible with exam
Take Home Message:
Everyone with a cervix is at risk for cervical cancer!

Contact me:
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amanda.fallin@uky.edu
Colorectal Cancer

Archana Maini, MD
Hematology/ Oncology
Broward General Medical Center
2017 LGBT HealthLink Summit
Objectives

- Colorectal cancer 101
- Epidemiology of colorectal cancer
- Colorectal cancer risk factors
- Colorectal cancer screening methods
- Colorectal cancer prevention and control
- Cost of treatment
- Building on what we know!
What is Colorectal Cancer?

- Small intestine
- Large intestine/colon/large bowel
- Rectum
What is Colorectal Cancer?

Polyps
- Hyperplastic
- Inflammatory
- Adenomatous

Dysplasias

95% colorectal cancer is adenocarcinoma
Adenoma to Carcinoma Pathway

- Normal Epithelium
- Hyperproliferation
- Early Adenoma
- Intermediate Adenoma
- Late Adenoma
- Cancer

- APC loss
- K-ras mutation
- Chrom 18 loss
- p53 loss
How Many People Get Colorectal Cancer?

- Third most common cancer in USA (among men and women) with cost of treatment about $6 billion a year

- Estimated cases for 2017
  - 135,430 people will be diagnosed with it

- Estimated death rate for 2017
  - 50,260 people will die from it
  - One million survivors in USA

CDC, 2013
Testing Status of adults aged 50-75

- Tested but not up-to-date 7%
- Never tested 28%
- Up-to-date CRC testing 65%

Source: BRFSS 2012
Risk Factors and Prevention
What Causes Colorectal Cancer?

Risk Factors:

- Age
- Ethnic background and race
- Diet, lack of exercise and overweight
- Smoking, alcohol and diabetes
- History of colorectal cancer in self or family
- History of polyps
- History of bowel disease
Reasons for Disparity in LGBT

- Smoking/ Drinking
- Obesity
- Relative poverty
- HCP stigma
- Lack of insurance
- Lack of awareness
- Lack of exercise
- Unbalanced diet
Can Colorectal Cancer be Prevented?

- Screening tests
- Diet and exercise
- Vitamin D, Calcium, Magnesium
- Aspirin and similar drugs
- Genetic testing
Early Detection, Diagnosis and Staging
How is Colorectal Cancer Found?

- FOBT (Fecal Occult Blood Test)
- FIT (Fecal Immunochemical test)
- Flexible sigmoidoscopy
- Colonoscopy
- Barium enema
- Virtual colonoscopy
<table>
<thead>
<tr>
<th></th>
<th>Colorectal Cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>AAFP</strong></td>
<td>No published standards or guidelines for low risk patients</td>
</tr>
<tr>
<td><strong>ACOG</strong></td>
<td>After age 50, annual FOBT (DRE should accompany pelvic exam); sigmoidoscopy every 3-5 years</td>
</tr>
<tr>
<td><strong>ACS</strong></td>
<td>After age 50, yearly FOBT and flex sigmoidoscopy plus DRE every 5 yrs or colonoscopy and DRE every 10 years or double contrast barium enema and DRE every 5 years</td>
</tr>
<tr>
<td><strong>AMA</strong></td>
<td>Annual FOBT beginning at age 50, and flex sigmoidoscopy every 3-5 years beginning at age 50</td>
</tr>
<tr>
<td><strong>CTFPHC</strong></td>
<td>Insufficient evidence to recommend using FOBT screening in older than 40 yrs. Insufficient evidence to recommend sigmoidoscopy or colonoscopy in the general population</td>
</tr>
<tr>
<td><strong>AGA</strong></td>
<td>FOBT beginning age 59; sigmoidoscopy every 5 yrs, double contrast barium enema every 5-10 yrs or colonoscopy every 10 years</td>
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<tr>
<td><strong>USPSTF</strong></td>
<td>After age 50, yearly FOBT and/ or sigmoidoscopy</td>
</tr>
<tr>
<td><strong>USPSTF</strong></td>
<td>After age 50, yearly FOBT and/ or sigmoidoscopy</td>
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</tbody>
</table>
How is Colorectal Cancer Diagnosed?

- Changes in bowel habits
- Bleeding
- Rectal fullness
- Cramping and abdominal pain
- Weakness and tiredness
- No symptoms
Treatment
How is Colorectal Cancer Treated?

3 main types of treatments

- Surgery
- Radiation therapy
- Chemotherapy/ Targeted therapy
Targeted Chemotherapy

Bevacizumab (Avastin)
- Annual cost per patient is $55,000

Cetuximab (Erbitux)
- Annual cost per patient is > $100,000

Panitumumab (Vectibix)
- Annual cost per patient is $100,000
Cost of Treatment

When detected early, individual treatment cost for colon cancer is estimated at $30,000 for a patient.
Cost of Treatment

The treatment cost for a patient who has developed late stage colorectal cancer is estimated at $120,000.
Cost of Treatment

If several new drugs are combined like Erbitux, Oxaliplatin, Irinotecan and Avastin, the annual cost per patient may reach ........
One Million Dollars!!!
Lessons learned from community-based cancer screening intervention research

<table>
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<tr>
<th>Access enhancement</th>
<th>Promotion</th>
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<td>Laws</td>
<td>Mass media</td>
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<tr>
<td>Nonclinical settings</td>
<td>Small media</td>
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<tr>
<td>Cost reduction</td>
<td>One-on-one education</td>
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<tr>
<td>Eliminate structural barriers (i.e., increasing healthcare coverage, using patient navigators)</td>
<td>Small-group education</td>
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<td>Incentives</td>
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<td>Reminders</td>
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</table>
Actionable Steps

- Goal is to screen 80% by 2018
- Campaign to get 80% of LGBT population over 50 years and older, screened for CRC
Doctors prescribe medicines of which they know little, to cure diseases of which they know less, in human beings of which they know nothing.

Voltaire (1694 – 1778)
Archana Maini, MD
Medical Research Director
Hematology/Oncology Division
Broward Health Center

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That Ass Tho!

increasing anal cancer screenings in the Lehigh Valley

Adrian Shanker
Executive Director
Bradbury-Sullivan LGBT Community Center
Creating a sex-positive, LGBT-focused, community-based campaign to address anal cancer screening among MSM populations.

This presentation is an example of a successful intervention in the Lehigh Valley region of Pennsylvania.
Prevalence of anal cancer is 34% times more common among MSM than the general population\(^1\), but in the Lehigh Valley region of Pennsylvania, it’s not discussed.

The HPV and Anal Cancer Foundation identifies several risk factors for Anal Cancer, including HPV, which is sexually transmitted through skin-to-skin contact, including during anal sex with or without condom usage. Receptive partners during anal sex and anyone with a weakened immune system, including people who are HIV+ are at increased risk for anal cancer\(^2\).

Tobacco use, which is significantly higher in the LGBT community, is also a leading cause of anal cancer.
Disparities between HPV-related cancers

70% of all cases of cervical cancer are caused by HPV\(^3\), and in Pennsylvania 90% of Pennsylvania women have had a cervical Pap test during their lifetime. However, 95% of anal cancer diagnoses are the result of HPV\(^3\) and only 8.9% of gay and bisexual men and 11% of transgender people in the Lehigh Valley have ever had an anal Pap test.

Stunningly, just one in four people who are HIV+ in the Lehigh Valley has ever had an anal Pap test despite the higher prevalence of anal cancer among people who are HIV+.\(^4\)
Barriers to Care

Most clinicians have not received training on anal Pap tests and most don't ask their patients if they need one. There are no clinical guidelines nationally or in Pennsylvania. Prior to this campaign, there was only one clinic in the Lehigh Valley offering anal Pap tests.

Anal Pap tests are not covered as a preventative screening by private health insurers in the Lehigh Valley. Insurance testing was conducted in August 2016 by Bradbury-Sullivan LGBT Community Center to confirm that the two largest private health insurers in the region (Capital BlueCross and Highmark Blue Shield) are not covering anal Paps as a preventative screening.
The Problem

Largest barrier is the lack of awareness

Prior to this campaign, there had only ever been one health promotion campaign on anal cancer for MSM populations - *Behind Closed Drawers* in NYC, created by The National LGBT Cancer Network.

Let’s expose anal cancer.
Lessons from Prior Campaigns

Advice from Liz Margolies, Executive Director, The National LGBT Cancer Network

“The sexier you make the campaign the better. Gay men love their tush, you have to make the campaign slightly suggestive. And in general, you want to make something that from a distance people want to pick up.”
That Ass Tho!

Clinical Training for one additional local clinic, to have two options for anal Pap tests in the community

Utilize Collective Impact model to develop a stakeholder committee to achieve a broadened community-wide impact

Development & broad implementation of a health promotion campaign to encourage MSM in the Lehigh Valley to seek anal Pap tests
Ethical considerations

Selection of the model
Costs of anal Pap tests with lack of insurance coverage
Local availability of follow-up tests
<table>
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<tr>
<th>Goals</th>
<th>Increase consumer demand</th>
<th>Increase clinical access</th>
<th>Increase Insurance coverage</th>
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</thead>
<tbody>
<tr>
<td><strong>Capstone</strong></td>
<td>Launch initial campaign</td>
<td>Train one additional clinic</td>
<td>N/A</td>
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<tr>
<td></td>
<td>20 consumers seeking anal Pap tests</td>
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<td><strong>End of 2017</strong></td>
<td>Replicate campaign in one additional community in Pennsylvania</td>
<td>Two additional clinical options for testing</td>
<td>Insurance coverage through one local insurer</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Clinical Guidelines from Physician General of Pennsylvania</td>
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<tr>
<td><strong>Long Term</strong></td>
<td>Next Lehigh Valley needs assessment (2018 or 2019) demonstrates a minimum of a 50% increase in anal Pap tests among gay and bisexual men</td>
<td>Primary Care Clinicians at Lehigh Valley health clinics routinely asking about anal Pap testing</td>
<td>Mandated coverage by Pennsylvania Insurance Commission for anal Pap tests as a preventative screening in all publicly supported insurance plans in Pennsylvania</td>
</tr>
</tbody>
</table>
Doubling clinical access in the Lehigh Valley

The clinical team at Allentown Women’s Center, a full-service sexual health clinic in Bethlehem, PA, was trained in January 2017, which doubled the number of clinical options for anal Pap tests in the Lehigh Valley.

Incentives for anal Pap tests were offered by Civic Theatre of Allentown. They offered a free film ticket for the first 20 people to receive an anal Pap test.
Engaging cross-sector stakeholders

A stakeholder committee was launched in January 2017 that included representatives from:

- Bradbury-Sullivan LGBT Community Center
- Lehigh Valley Health Network
- Allentown Women’s Center (participating clinic)
- NOVUS ACS (participating clinic)
- Planned Parenthood Keystone
- Muhlenberg College
- Metropolitan Community Church of the Lehigh Valley
- Equality Pennsylvania
Launch Event

BEST ASS CONTEST
and the launch of a new sexual health campaign
That Ass Tho:
promoting anal cancer screening for gay & bi men
January 28, 2017 at 11:30pm
Stonewall Lehigh Valley
28 N. 10th St., Allentown, PA

21+ event, $5 cover charge at the door

Hosted by:

Stonewall
Lehigh Valley

Bradbury-Sullivan
LGBT Community Center
Serving the LGBT Community
of the Greater Lehigh Valley

photo credit: Andrew Tomasino
The Campaign

Campaign Design

- Branding with trusted local source (Bradbury-Sullivan LGBT Community Center)
- Graphically strong
- Sex-positive title and tagline
- Clear information
- Local clinical options
- Easily accessible additional information
- Bilingual (English/Spanish) campaign
- Hired professional photographer, model, and graphic designer
Targeted Ad Placement:
Muhlenberg College Newspaper
Lehigh Valley Gay Journal
Posters and postcards in gay bars, health clinics, LGBT community spaces, and colleges

Direct Outreach:
Lehigh University Service Learning Class
Bradbury-Sullivan LGBT Community Center community outreach
Anal Paps

Seven community members sought anal Pap tests at the two participating clinics with 4 receiving anal Pap tests. The goal was 20 people seeking the test and 10 receiving it. Lack of insurance coverage and lack of access through an individual's primary care doctor proved to be serious barriers to care.

Policy Change:

Presentation to Governor’s LGBT Workgroup

PA Physician General asked for draft of clinical guidelines

Met with representatives of Capital BlueCross and Highmark Blue Shield

Future conversations planned with PA Insurance Commissioner’s office
Lessons Learned

Lack of insurance coverage is a significant cost barrier.

Inability to receive an anal Pap test from most primary care clinicians is a significant barrier, more clinical options are needed in general.

Challenges with labs delayed the start-up process.

More public education is needed.
Replication of Campaign
Coatesville Area Youth Philanthropy Program has funded a grant to replicate That Ass Tho! in the Greater Coatesville Area of Pennsylvania in Summer 2017

Lehigh Valley Clinical Access:
Ongoing conversations with three additional clinics who are considering offering anal Pap tests.


Contact information:

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www.bradburysullivancenter.org
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**LGBTHL17**

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• Members-only online networking groups
• Exclusive webinars and resources
• Co-branding opportunities

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Facebook: LGBT HealthLink
Twitter: @LGBTHealthLink