FINDINGS FROM MIDTERM NEEDS ASSESSMENT

May 2022

NATIONAL LGBT CANCER NETWORK
Introduction

This report summarizes the current state of LGBTQ+ inclusive practices among State and Territory Comprehensive Cancer (CCP) and Tobacco Control Programs (TCP) based upon alignment with the National LGBT Cancer Network’s seven best and promising practices. The midterm assessment asked CCPs and TCPs about their activities and efforts to engage LGBTQ+ populations between April 2019 and December 2020.

At baseline (Jan. to Apr. 2019), we found that a minority of programs (38%) were moderately (5-6 best practices) to highly inclusive (7 best practices), including 27% of CCPs and 49% of TCPs. Through our networking, training, and technical assistance, we increased the number of moderately and highly inclusive programs to almost half (49%) of all programs at midterm, including 40% of CCPs and 58% of TCPs. We found that almost half (47%) of programs increased the total number of best practices during this period, including 48% of CCPs and 45% of TCPs. This overall improvement in LGBTQ+ inclusive practices is remarkable given the unprecedented challenges navigating the COVID-19 pandemic. During this same period, we engaged in several activities that supported this improvement in LGBTQ+ inclusive practices, including:

- Providing cultural humility trainings for CCPs and TCPS
- Creating LGBTQ+ tailored materials for cancer screenings and tobacco cessation
- Fostering relationships between state programs and LGBTQ+ community partners
- Supporting programs with implementing a needs assessment of LGBTQ+ populations
- Advocating for increased/enhanced data collection on LGBTQ+ populations, including the inclusion of the sexual orientation and gender identity (SOGI) module with the Behavioral Risk Factor Surveillance System (BRFSS)
In this report, we highlight the current status for each of our seven best and promising practices among both CCPs and TCPs at midterm (Apr. 2019 - Dec. 2020). For each best practice, we provide a summary of the number of programs that met this objective, thus receiving a check mark on their scorecard, at both baseline and midpoint as well as a breakdown for each of the related activities. We also highlight quotes from programs about their work. Based on our analysis, some of our key findings include:

- CCPs and TCPs experienced a sudden shift in staffing capacity and resources due to the COVID-19 response that limited program activities and delayed community partnerships.
- There was an overall decrease in the number of programs with LGBTQ+ employees, including those in leadership positions.
- The majority of TCPs include LGBTQ+ specific goals in their work plan and help community partners to develop LGBTQ+ specific goals, while less than half of CCPs have LGBTQ+ specific goals.
- There was a significant increase in the number of states collecting SOGI data on BRFSS (40 states in 2021).
- Approximately half of programs offered or used trainings in LGBTQ+ cultural competency.
- There was an overall decrease in the number of programs funding LGBTQ+ community-based organizations, likely due to the impact of COVID-19, particularly the cancelation of Pride events in 2020.
- There was a significant increase in the number of programs using LGBTQ+ tailored resources from the National LGBT Cancer Network.
- TCPs were more than twice as likely to have analyzed and disseminated their findings specific to LGBTQ+ populations compared to CCPs.
Looking ahead, this report highlights areas of improvement for the latter half of our funding period. For example, we can provide technical assistance to the 29 programs that were rated as minimally (1-2 best practices) or non-inclusive (0 best practices), including 18 CCPs and 11 TCPs. Moreover, we can leverage the experiences of the 55 programs rated as moderately or highly inclusive to share lessons learned on how states can better engage LGBTQ+ populations in the cancer or tobacco work. Lastly, we will continue our advocacy efforts to encourage adoption of the SOGI module as a standard questionnaire on BRFSS.

Dr. Scout
Executive Director, National LGBT Cancer Network
Overview

As part of our evaluation plan with the Centers for Disease Control and Prevention’s (CDC) Networking to Save, we conducted a midpoint needs assessment among CDC-grantee cancer and tobacco programs across all US states and territories. This survey is a follow-up to our baseline assessment, which was conducted in Spring 2019. Therefore, the reference period is April 2019 - December 2020. We used the survey instrument from the baseline assessment with only minor modifications, including new questions related to the impact of COVID-19. The survey is designed to measure program activities during the reference period in alignment with our seven best and promising practices for engaging lesbian, gay, bisexual, transgender, and queer (LGBTQ+) populations in tobacco and cancer work. These practices include:

1. Promote LGBTQ+ professional safety and leadership in public health.
2. Include LGBTQ+ community members in policy planning steps.
3. Monitor impact of tobacco/cancer on LGBTQ+ populations.
4. Establish cultural competency standards for agency and agency-funded programs.
5. Fund community-based programs.
6. Routinely integrate LGBTQ+ tailored materials into larger campaigns
7. Disseminate findings and lessons learned.

Each best practice is associated with one or more program activities. For the midpoint assessment, each state cancer or tobacco program received a check mark for the best practice if they reported completing at least one of the related activities during the reference period (April 2019 - December 2020). Overall ratings were as follows:

- Highly Inclusive: 7 best practices
- Moderately Inclusive: 5-6 best practices
- Somewhat Inclusive: 3-4 best practices
- Minimally Inclusive: 1-2 best practices
- Non-Inclusive: 0 best practices
The survey took approximately 15 minutes to complete and was self-administered via Qualtrics, an online survey platform. Primary contacts from each CDC-grantee cancer and tobacco in all US states and territories (118 total programs) were invited via email to complete the survey. All participants were provided their 2019 scorecard, overview of the best and promising practices, and a copy of the survey instrument to review before completing the midpoint assessment. After completing the survey, participants were sent their new scorecard to review and could update their responses after consulting with other team members if needed. The midpoint assessment was open from November 2020 until February 2021.

The overall response rate by program is:
- **Cancer:** 90% response rate among US state and territory programs (n=53/59)
  - 51 US state and territory programs completed the baseline assessment (86% response rate)
  - 2 state programs that completed baseline assessment did not participate in midpoint assessment
  - 4 territory programs that did not complete baseline assessment participated in midpoint assessment
  - 4 territory programs did not complete both baseline and midpoint assessment
- **Tobacco:** 100% response rate among US state and territory programs (n=59/59)
  - 53 US state and territory programs completed the baseline assessment (90% response rate)
  - 6 territory programs that did not complete baseline assessment participated in midpoint assessment
At the midpoint assessment, we found that approximately half (49%, n=55) of the CDC-grantee cancer and tobacco programs surveyed were rated as moderately (5-6 best practices) or highly inclusive (7 best practices) with regards to the program activities specific to engaging LGBTQ+ populations in their work from April 2019 - December 2020. Specifically, 21 cancer programs (40%) and 34 tobacco programs (58%) received this rating. This is an overall increase in the number of programs rated as moderately or highly inclusive from baseline for both cancer and tobacco programs.

Approximately 42% of programs (n=47) were rated as somewhat (3-4 best practices) or minimally (1-2 best practices) inclusive. Specifically, 27 cancer programs (51%) and 20 tobacco programs (34%) received this rating. A minority of programs (9%, n=10) were rated as non-inclusive, meaning that they did not report any best practices for engaging LGBTQ populations. Among the 10 programs rated as non-inclusive at midpoint, 3 tobacco programs and 1 cancer program did not complete the baseline assessment.
Compared to baseline, almost half (47%, n=48) of programs increased the number of best practices, with 24 cancer programs and 24 tobacco programs represented. A total of 29 programs (28%) did not change in the number of practices, with 11 cancer programs and 18 tobacco programs represented. Among those with no change, a total of 2 cancer programs and 5 tobacco programs maintained a highly inclusive rating (all 7 best practices) from baseline to midpoint. A minority of programs (25%, n=25) decreased in the number of best practices, driven largely by the impact of the COVID-19 response (discussed in next section).
Inclusiveness Rating Overview:
- 21 cancer programs are moderately or highly inclusive compared to 14 cancer programs at baseline
- 27 cancer programs are minimally or somewhat inclusive compared to 29 cancer programs at baseline
- 5 cancer programs are non-inclusive compared to 8 cancer programs at baseline

"We tailored our Wisconsin Cancer Plan 2020-2030 to be more LGBTQ friendly - with photos and indicating LGBTQ specific needs. We've also done social media to promote various resources and activities of the National LGBT Cancer Network"
- Wisconsin CCP
Inclusiveness Rating Overview

- 34 tobacco programs are moderately or highly inclusive compared to 29 tobacco programs at baseline
- 20 tobacco programs are minimally or somewhat inclusive compared to 22 tobacco programs at baseline
- 5 tobacco programs are non-inclusive compared to 2 tobacco programs at baseline (Note: 3 of these programs did not complete the baseline measurement)

"National LGBTQ Cancer Network presented to staff and grantees about how to expand reach and engagement with LGBTQ populations."
- Kansas TCP
Impact of COVID-19

In March 2020, the onset of the COVID-19 global pandemic suddenly and drastically impacted how CDC-grantee cancer and tobacco programs implemented their work plans. This resulted in a shift to remote work and virtual programming, which continued into 2021 for many programs. Similarly, staff time was re-directed towards the COVID-19 response, with some programs having their entire team being re-assigned to COVID-19 efforts for several months.

For cancer programs, many reported limited outreach and engagement in cancer clinics due to the shift to telemedicine and increased risk of COVID-19 among people living with cancer. Many cancer programs also cited concerns about the significant drop in cancer screenings due to social distancing measures. For much of their work, community-based projects were stalled indefinitely as it was difficult to sustain and build new partnerships virtually. Several programs described how they faced significant challenges to meet grant deliverables and struggled to sustain activities to engage LGBTQ populations as a result.

There is a renewed interest in health equity, since the COVID-19 pandemic has really highlighted how health disparities and barriers are still very prevalent in our society.”
- Iowa CCP

“It has greatly impacted our ability to continue working at an optimal level in our programs. The staff we had working in the Comp Cancer program have been temporarily reassigned to COVID vaccine and flu vaccine work.”
- Missouri CCP
For tobacco programs, partnerships with community organizations were impacted as they also shifted focus during the pandemic, with many large events such as Pride being canceled and some organizations losing staff and funding due to shifting priorities. It was also challenging to establish new community partnerships during this period. For example, partnerships with schools and other youth organizations were impacted due to the shift to virtual learning, which made distribution of materials more difficult. Some tobacco programs responded to the pandemic by designing materials to highlight the increased risk of COVID severity among tobacco users. Even so, several programs had difficulty completing grant work plans as a result of these challenges, resulting in fewer activities to engage LGBTQ populations in their work.

“A lot of staff responded to Covid-19 and it impacted our tobacco-related work. We are just now getting back to tobacco-related work.”  
- Alabama TCP

“The pandemic has resulted in challenges in establishing new partnerships for tobacco free and smoke free policy work. Policy work with organizations such as schools and health care facilities have also slowed while organizations adjust operations during the pandemic.”  
- Alaska TCP
Overall, there was an increase in the number of programs that reported one or more activities related to promoting LGBTQ+ professional safety and leadership in public health: 34 cancer programs received a check mark for BP #1 compared to 32 cancer programs at baseline and 38 tobacco programs received a checkmark for BP #1 compared to 36 tobacco programs at baseline.

At midpoint, the most common activity was to have LGBTQ representatives in advisory groups (51%, n=57), including 28 cancer programs and 29 tobacco programs. Approximately one-third of programs have openly LGBTQ staff in leadership roles (32%, n=36), including 18 cancer programs and 18 tobacco programs. Approximately one-quarter of programs recruited & hired LGBTQ employees (26%, n=29), including 15 cancer programs and 14 tobacco programs. The least common activity was to form a workplace LGBTQ task force or working group (20%, n=22), including 7 cancer programs and 15 tobacco programs.
Despite the small increase in the number of programs receiving a check mark for this best practice, there was a decrease in most of the activities. Most notably, fewer programs recruited and hired LGBTQ employees and had openly LGBTQ staff in leadership roles. Compared to baseline, the only activity with significant improvement was the formation of a workplace LGBTQ task force.
Best Practice #1

Promote LGBTQ+ Professional Safety and Leadership in Public Health

Formed Workplace LGBTQ+ Task Force or Working Group

Had Individual LGBTQ+ Representatives in Advisory Groups

Since April 2019, CTCP has worked to promote the safety of LGBTQ staff by updating its internal event planning business rules and best practices to promote gender inclusivity and preferred pronoun usage. - California TCP
Best Practice #1

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We want to create a space where people feel comfortable being authentic and sharing personal information.”
- Kansas CCP

“At our October 2019 MCC Annual Meeting, we had a keynote panel of 3 individuals who shared their journey in healthcare related to their LGBTQ status. One of the panel members was later selected to be the chair of the Michigan Cancer Consortium Health Equity Committee during Michigan's Cancer Plan process.”
- Michigan CCP

“We are encouraging our State and Community Intervention Partnership coalitions in each county to reach out to LGBTQ groups in their counties to invite participation. Students Working Against Tobacco (middle and high school youth) included pronoun identification during their annual meeting.”
- Florida TCP
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Overall, there was an increase in the number of programs that reported one or more activities related to including LGBTQ+ community members in policy planning steps: 35 cancer programs received a checkmark for BP #2 compared to 23 cancer programs at baseline and 47 tobacco programs received a checkmark for BP #2 compared to 38 tobacco programs at baseline.

"As a population with tobacco use higher than the rest of the population, the LGBTQ community is one of our focus areas in tobacco control. The Virginia TCP began a relationship years ago with Q Magazine, a locally owned LGBTQ-focused statewide publication."

- Virginia TCP
Best Practice #2

Tobacco programs were more likely to have LGBTQ+ specific goals in their work plan than cancer programs, with 43 tobacco programs compared to 23 cancer programs. This was an overall increase from baseline.

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<tr>
<th></th>
<th>Cancer</th>
<th>Tobacco</th>
<th>Overall</th>
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<tbody>
<tr>
<td>Baseline</td>
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<td>50</td>
<td>25</td>
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<tr>
<td>Midpoint</td>
<td>25</td>
<td>50</td>
<td>75</td>
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Approximately six in ten programs (59%, n=66) helped grantees add LGBTQ+ specific goals to their work plans, including 27 cancer programs and 39 tobacco programs. This was an overall increase from baseline.
Best Practice #2

“Every time the state cancer coalition has convened, community partners with an emphasis in LGBTQ healthcare, programming and engagement have been invited to participate and serve as content experts during objective development.”
- Arizona CCP

“Since April 2019 we have updated our State Cancer Plan. LGBTQ community members were engaged in updating the Cancer Plan and the Objectives, Goals, and Strategies.”
- Maryland CCP

“Project Filter sub-grants with 7 public health districts in Idaho to work with their local communities. A key focus of the sub-grants is to work to increase smoke free areas affecting LGBTQ and pride events.”
- Idaho TCP
Best Practice #3

Overall, there was an increase in the number of programs that reported one or more activities related to monitoring the impact of tobacco and cancer on LGBTQ+ populations: 38 cancer programs received a check mark for BP #3 compared to 26 cancer programs at baseline and 44 tobacco programs received a checkmark for BP #3 compared to 43 tobacco programs at baseline.

For the midpoint assessment, we surveyed Behavioral Risk Factor Surveillance System (BRFSS) coordinators to determine whether or not their state or territory module includes the standard sexual orientation and gender identity (SOGI) module on BRFSS. Approximately two-thirds of programs (65%, n=73), including 35 cancer programs and 38 tobacco programs, are in states that included the SOGI module on the 2020 cycle for BRFSS. This reflects an overall increase in the number of states collecting SOGI data on BRFSS from baseline.

“We included new SOGI measures for our new Wisconsin Cancer Plan 2020-2030”
- Wisconsin CCP
As part of our on-going technical assistance, we work with state BRFSS coordinators to identify and address barriers to implementing the standard SOGI module. In 2019, we published our first data brief on SOGI data collection on BRFSS, which was updated in 2021. Our long-term goal is to advocate for the adoption of the SOGI module as part of the core questions included on BRFSS to measure and track health disparities among sexual and gender minority populations.

“We have collected SOGI data for over 10 years. Actually, the tobacco control program initially requested and subsequently paid for the BRFSS questions to assure inclusion. In so doing, not only tobacco but all DOH programs have years of data.”
- Hawaii TCP
Best Practice #3

Monitor Impact of Tobacco and Cancer on LGBTQ+ Populations

“We have been able to utilize community based surveys to collect data that impact LGBTQ at community events, targeted focus groups, and annual conferences”
- Mississippi CCP

Compared to baseline, there was an increase in the number of state programs collecting SOGI data on local surveys, including community-based surveys, needs assessments, and research surveys. Overall, tobacco programs were more likely to have collected data specific to LGBTQ+ populations than cancer programs, with 14 tobacco programs and 10 cancer programs. Even so, less than one-quarter of programs include SOGI-specific questions on local surveys (21%, n=24), which is vital for monitoring the impact of cancer and tobacco on LGBTQ+ populations.

![Community-Based Survey(s)]

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<th>Baseline</th>
<th>Midpoint</th>
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<tbody>
<tr>
<td>Cancer</td>
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<tr>
<td>Tobacco</td>
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<td>20</td>
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<tr>
<td>Overall</td>
<td>20</td>
<td>40</td>
</tr>
</tbody>
</table>

“We utilize data on tobacco use for individuals who identify as LGBTQ+ to drive our programming, educate partners to serve people who identify as LGBTQ+, and to advocate for funding focus for programs.”
- Michigan TCP
Best Practice #4

Offered or Used Training in LGBTQ+ Cultural Competency

Overall, there was an increase in the number of programs that reported they offered or used trainings in LGBTQ+ cultural competency: 26 cancer programs received a check mark for BP #4 compared to 24 cancer programs at baseline and 30 tobacco programs received a checkmark for BP #4 compared to 28 tobacco programs at baseline.

Approximately half of programs (50%, n=56) offered or used trainings in LGBTQ+ cultural competency, which was the only related activity for this best practice. This is an overall increase from baseline.

“Our program has promoted cultural competency trainings which include LGBTQ cultural competency, along with developing competency for working with other populations.”
- Texas CCP
“We have used training in LGBTQ cultural competency for Illinois Tobacco Quitline counseling and intake staff.”
- Illinois TCP

“We have trained over 86 mammography providers in LGBTQ cultural and health delivery competency. This includes recommending structural changes to systems and environmental changes
- Ohio CCP

“Oregon Health Authority offers trainings on SOGI data and ensuring inclusion of questions and demographics that are inclusive of the diversity of Oregon.”
- Oregon TCP
Overall, there was a decrease in the number of programs that funded community-based programs to help reduce tobacco and cancer disparities among LGBTQ+ populations. This was driven by a decrease in the number of cancer programs that provided funding: 10 cancer programs funded LGBTQ+ community-based programs compared to 14 cancer programs at baseline.

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<thead>
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<tr>
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<tr>
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<td>Overall</td>
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<td>50</td>
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This decrease was driven largely by challenges related to the COVID-19 pandemic, including diverted funding and difficulty collaborating with community-based organizations, and is the only best practice with a recorded decrease in programs from baseline to midpoint. Approximately one-third of programs (31%, n=35) funded LGBTQ+ community-based programs, which was the only related activity for this best practice. Tobacco programs were more than twice as likely to fund LGBTQ+ community-based programs compared to cancer programs.
Best Practice #5

Funding that is directly used for educational materials has been taken from the program and reallocated for COVID-19 use.
- North Carolina CCP

Project Filter funds five of the six Pride organizations in Idaho. We also funded the first LGBTQ health care conference in October 2019.
- Idaho TCP

The RIDOH CCC Program has led the department's engagement in funding LGBTQ community-based programs. Since April of 2019, we have sponsored the RI Trans* Health Conference, participated in RI Pride, and written SGM health equity work into the contractual scope of work of our state cancer coalition.
- Rhode Island CCP

As a response and solution to COVID-19 challenges, local LGBTQ tobacco programs have attended and hosted online LGBTQ events and meetings to engage LGBTQ communities on issues related to tobacco-use.
- California TCP
Best Practice #6

Overall, there was an increase in the number of programs that reported they routinely integrate LGBTQ+ tailored efforts into larger cancer wellness and tobacco campaigns: 36 cancer programs received a checkmark for BP #6 compared to 26 cancer programs at baseline and 46 tobacco programs received a checkmark for BP #6 compared to 36 tobacco programs at baseline.

Best Practice #6

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<tr>
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<tr>
<td>Tobacco</td>
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<td>Overall</td>
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<td>75</td>
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“We have utilized social media to promote success stories around screening and survivorship with LGBTQ participants speaking directly to the LGBTQ audience”
- Mississippi CCP
Over half of programs (59%, n=66) used tailored resources from the National LGBT Cancer Network, including 32 cancer programs and 34 tobacco programs. This was a significant improvement from baseline, with more than double the number of programs using resources from the National LGBT Cancer Network.

Tobacco programs were twice as likely to have used tailored educational or promotional materials for LGBTQ+ populations, with 16 cancer programs and 36 tobacco programs.
Best Practice #6

The most common tailored activities for LGBTQ+ populations included tobacco cessation and health promotion programs.

Cancer Programs - LGBTQ+ Tailored Programs

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<th>Health Promotion</th>
<th>Health Promotion</th>
<th>Baseline</th>
<th>Midpoint</th>
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<td>Cessation</td>
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<td>Screening</td>
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<td>Survivorship</td>
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Tobacco Programs - LGBTQ+ Tailored Programs

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<td>Survivorship</td>
<td>Survivorship</td>
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“Had screening and cessation materials reviewed & revised for better communications with LGBTQ audience; ensuring language was more inclusive, etc.”
- Connecticut TCP

“We have a postcard ready to send to people with addresses from the Ohio Quitline. The images we selected are LGBTQ represented for this initiative. That is a first for Ohio and this initiative; openly welcoming LGBTQ to take advantage of these free screenings.”
- Ohio CCP

“Working on approval of co-branded National LGBT Cancer Networks cancer screening postcards. Working with the Maine CDC Tobacco Program on LGBTQ+ and cancer cessation efforts through the Maine QuitLink.”
- Maine CCP

“We ran a social media campaign in April and May 2020 educating LGBTQ tobacco users of the risk related to smoking and COVID-19 recovery/severity and promoting cessation and free assistance from the MO Tobacco Quitline.”
- Missouri TCP

Routinely Integrate LGBTQ+ Tailored Efforts into Campaigns
Overall, there was an increase in the number of programs that reported they disseminated their findings and lessons learned, driven by a significant increase among tobacco programs: 17 cancer programs received a check mark for BP #7 compared to 17 cancer programs at baseline and 40 tobacco programs received a checkmark for BP #7 compared to 30 tobacco programs at baseline.

“We have disseminated national data and State BRFSS data to our partners, on our website and our internal partners. We are conducting a second LGBTQ+ survey on tobacco use this year through our LGBT funded agencies.”
- Michigan TCP
Best Practice #7

At the midpoint assessment, tobacco programs were more than twice as likely to have analyzed and disseminated their findings specific to LGBTQ+ populations compared to cancer programs.

Overall, fewer programs shared their findings, even though almost half analyzed data specific to LGBTQ+ populations (46%, n=51). It is important that state programs not only collect and analyze data specific to LGBTQ+ populations, but share their results and lessons learned with their community of practice.
"Use of the National LGBTQ Cancer Networks inaugural needs assessment to influence priorities of programs agency wide."
- West Virginia CCP

"Our Cancer Coalition hosted a partners meeting on LGBTQ screening navigation and barrier reduction and shared findings in that meeting”
- Colorado CCP

"Tobacco use rates for LGBTQ populations were included in the TPCP's annual reports and in data presentations at all partner meetings.”
- Utah TCP

"We produced a data brief for the RI Trans* Health Conference summarizing BRFSS and YRBS SGM health risks and protective factors.”
- Rhode Island CCP