

# Late-Stage Diagnosis of Unscreened Cancer: a Health Disparity

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### Executive Summary

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The National Minority Quality Forum (NMQF), seeks to raise awareness of the disproportionate impact of unscreened cancers among racial and ethnic minority groups. The findings from this research are intended to highlight the role of early detection in improving outcomes, particularly in minority populations, and support broader discussion on where opportunities may exist to address disparities.

There has been significant progress in cancer outcomes in recent years, as evidenced by reductions in cancer death rates and survival improvements across many forms of the disease. While outcomes for minority populations have also improved over time, many of these communities continue to bear a disproportionate cancer burden. Across many cancers, racial/ethnic minority communities are more likely to have cancer diagnosed at a later stage and, as a result, have higher mortality rates as compared to non-Hispanic Whites (NHW).

Across all cancer types, outcomes improve when cancer is detected earlier. However, according to the American Cancer Society (ACS), early detection tests with a recommended screening are only available for 5 cancer types (breast, cancer, colorectal, lung, and prostate), leaving many cancers without screening tools (these are termed “unscreened cancers”).<sup>1</sup> Unfortunately, late-stage diagnoses for these unscreened cancers is more common in minorities, and outcomes are often worse. Extending the benefits of early detection to more cancers and more people could improve outcomes for cancer patients across the board. While there have been successes in increasing screening rates among minority patients, there is a need to increase screening rates and ensure equitable access to new screening technologies, expanding the benefits of early detection to more people and more cancers. The following white paper provides key data points demonstrating the impact of cancer health disparities for minority communities. In review of data and current research, this white paper suggests policy changes needed to eliminate some of these disparities and allow minority populations to benefit from early detection.

### Introduction: Despite Progress in Detection, Late-Stage Diagnosis of Unscreened Cancers Remains Disproportionately Higher in Minority Communities

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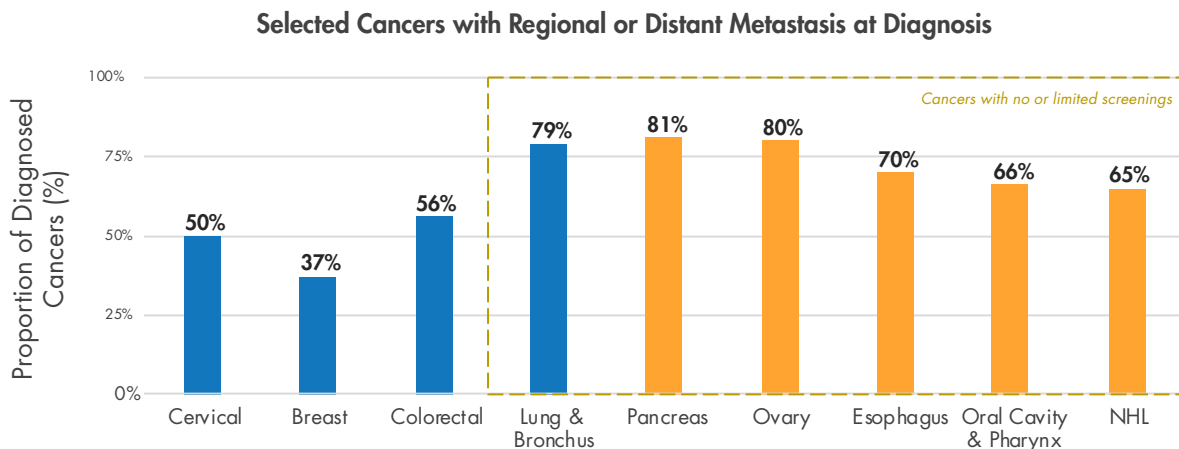
In recent decades, significant scientific, clinical, and technological advancements have helped drive improvements in cancer outcomes. Between 2008 and 2017, cancer death rates dropped by an average of 1.5% per year, resulting in over 3.2 million avoided deaths since 1991.<sup>2</sup> Improvements in preventive measures have a significant impact in bending this mortality curve, including reductions in tobacco use and increases in early detection. However, cancer is still the second leading cause of death in the United States<sup>3</sup> and, in 2021, cancer-related deaths could reach nearly 609,000.<sup>4</sup> Cancer-related care also puts a large burden on our health care system. In 2018, cancer-related care in the US made up approximately \$150 billion dollars in national expenditures, and that number is expected to grow as the population ages.<sup>5</sup> Most recently, the ongoing COVID-19 pandemic has led to significant drop in cancer screenings and delays in testing and treatment, and many cancer experts are concerned that the reduction in early detection will lead to an increase in late-stage cancer and preventable cancer deaths.<sup>6</sup>

**Disparities in cancer outcomes are driven by a variety of factors, including environmental, behavioral, social, clinical, and cultural factors.**<sup>7</sup> The ACS states that “the causes of these inequalities are complex and reflect social and economic disparities and cultural differences that affect cancer risk, as well as differences in access to high-quality health care, more than biological differences.”<sup>8</sup> These disparities exist among minorities even when various clinical and sociodemographic factors, such as cancer type, site of care, insurance status, income, and education level, are taken into account. Barriers to access can affect when an individual decides to seek care and delay receipt and utilization of cancer-related services, particularly among racial and ethnic minorities.<sup>9</sup> These factors contribute to racial and ethnic minorities being diagnosed in later or more advanced stages of cancer compared to NHW individuals, which contributes to overall poorer outcomes, including increased mortality.<sup>10,11</sup> When considering all cancers combined, Black Americans have higher cancer mortality rates than any other racial group, and cancer remains the leading cause of death for Asians and Hispanics.<sup>12,13</sup>

## Variations in Stage of Diagnosis

**The stage at which cancer is diagnosed often plays a significant role in determining a patient’s prognosis.**<sup>14</sup> At diagnosis, cancer is typically staged from 0 to IV or categorized as localized (stage I), regional (stage II), and advanced (stage III and IV), with each advancing stage referring to an increase in the extent and spread of cancer. For many cancers, diagnosis often occurs at later stages, after symptoms have developed.<sup>15</sup> This is particularly true of unscreened cancers, which are more likely to be diagnosed in later or more advanced stages.<sup>16</sup> For example, about half of all cervical and colorectal cancer diagnoses are at regional or distant metastasis, compared to over 80 percent of pancreatic and ovarian cancers are diagnosed late stage (Figure 1). Metrics like 5-year survival and mortality can help to understand trends and serve as predictors of screening and early detection’s longer-term impact on outcomes.<sup>17</sup>

**Figure 1. Many Unscreened Cancers Are Diagnosed at Late Stage, 2015-2018**



NHL, non-Hodgkin lymphoma; USPSTF, United States Preventive Services Task Force. Siegel R, et al. Cancer Statistics, 2018. CA Cancer J Clin. 2018;68(1):7-30.

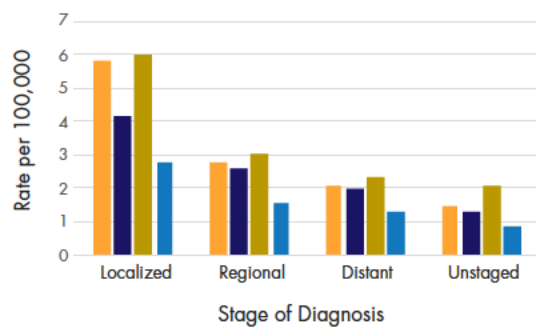
## Late-Stage Diagnosis of Unscreened Cancer: a Health Disparity

**Racial and ethnic minority cancer disparities persist when considering stage of diagnosis.** Across several unscreened cancers, such as esophageal, ovarian, pancreatic, and stomach, Black, Hispanic, and American Indian/Alaska Native (AI/AN) individuals are more often diagnosed in the distant, or later, stages of cancer compared to NHW individuals (Figure 2).<sup>18</sup> For example, 2008-2017 data show that Black patients with pancreatic cancer were diagnosed with distant cancer at higher rates compared to NHW patients (8.0 per 100,000 vs. 6.5 per 100,000).<sup>19</sup> In stomach cancer, Black, Hispanic, and AI/AN have higher rates of distant cancer diagnoses compared to NHW patients (3.1 per 100,000, 3.4 per 100,000, 3.7 per 100,000 vs. 2.0 per 100,000). In lung cancer, where there are established recommendations for screening of high-risk individuals, late-stage diagnoses continue to present challenges generally, and while most individuals with lung cancer are diagnosed at a distant stage, the proportion of Black individuals diagnosed at a distant stage is higher at 53% compared to NHWs at 49%.<sup>20</sup>

**Figure 2. Stage of Diagnosis by Race, Selected Unscreened Cancers**

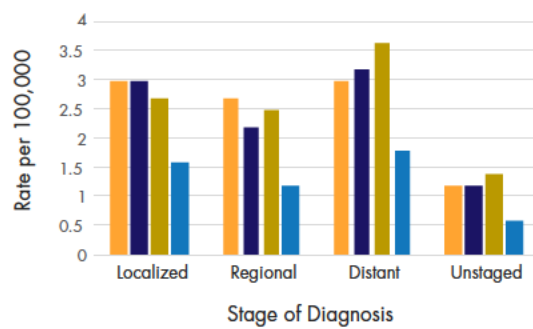
### Liver and Intrahepatic Bile Duct Cancer

SEER 5-Year Age-Adjusted Incidence Rates, 2014-2018 By Stage of Diagnosis and Race/Ethnicity, Both Sexes, All Ages



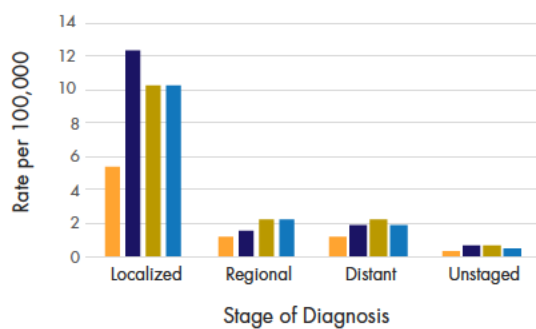
### Stomach Cancer

SEER 5-Year Age-Adjusted Incidence Rates, 2014-2018 By Stage of Diagnosis and Race/Ethnicity, Both Sexes, All Ages



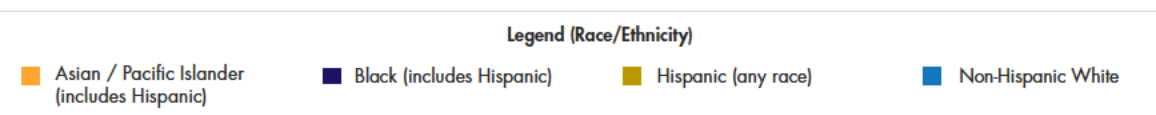
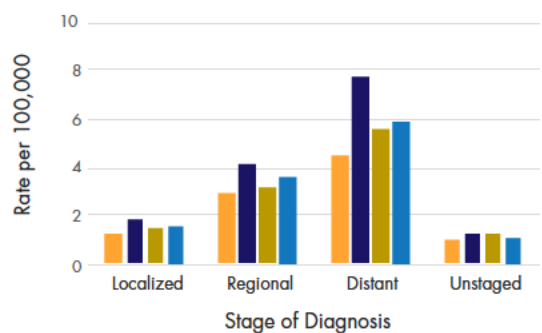
### Kidney Cancer

SEER 5-Year Age-Adjusted Incidence Rates, 2014-2018 By Stage of Diagnosis and Race/Ethnicity, Both Sexes, All Ages



### Pancreas Cancer

SEER 5-Year Age-Adjusted Incidence Rates, 2014-2018 By Stage of Diagnosis and Race/Ethnicity, Both Sexes, All Ages



Source: Surveillance, Epidemiology, and End Results Program (SEER) and National Program of Cancer Registries (NPCR) data, 2013 -2017

## Stage of Diagnosis Impacts Cancer Outcomes, Highlighting the Importance of Earlier Detection

This section discusses improved outcomes by stage generally, and is followed by data showing the impact among minority groups of earlier detection on 5-year survival for several cancers. Across all cancers, later stage diagnosis is associated with an increased risk of poorer outcomes, including higher rates of mortality. Surveillance, Epidemiology, and End Results (SEER) data from 2008 to 2017 showed that individuals who were diagnosed with distant metastases had an average 79% 5-year mortality rate across cancer types.<sup>21,22</sup> This compares to an average mortality rate of only 11% when cancer is diagnosed when the tumor is localized.<sup>23</sup>

Early detection using recommended screenings and subsequent earlier stage diagnoses can play a key role in improving cancer outcomes, including relative survival rate after diagnosis. For many cancers, an early cancer diagnosis may mean more available treatment options and higher chances of successful intervention. An examination of cancer data suggests that 5-year relative survival rates for certain cancers could increase by as much as 90% when screening tools are used before symptoms arise.<sup>24</sup>

Cancer survival trends across various cancer types exemplify a strong correlation between the use of targeted cancer programs focused on early-stage diagnosis and improved survivorship.<sup>25</sup> For example, 63% of patients diagnosed with stage I or stage II, localized non-small cell lung cancer have higher 5-year survival rates compared to only 7% of patients diagnosed with a later-stage diagnosis, stage IV lung cancer.<sup>26</sup> The benefits of cancer screening on life expectancy are observed in many types of cancers, specifically for those comprehensive screening recommendations. According to SEER data from 2008 to 2017, 5-year relative survival of cancers ranged between 30 – 80% when diagnosed early compared to later-stage diagnoses (Table A). Concerted efforts from healthcare stakeholders to improve screening guidelines for early detection among typically unscreened cancers could prove beneficial.<sup>27,28</sup>

**Table A. Survival Rates are Higher When Cancer is Diagnosed at an Earlier Stage (Various Cancers), 2010-2016**

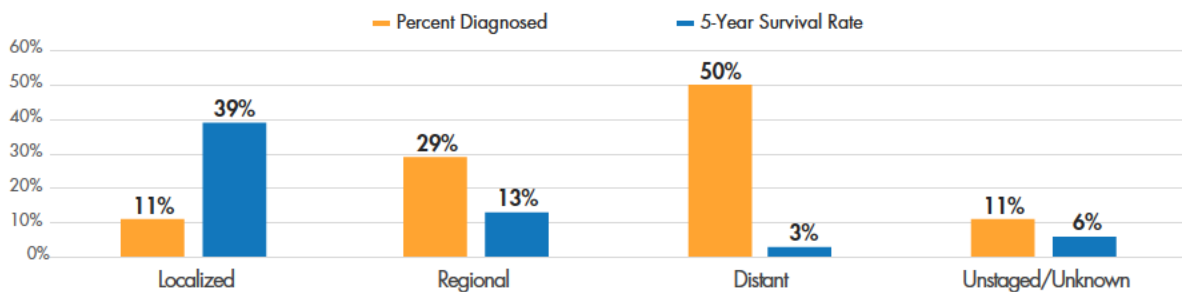
5-Year Relative Survival Rates for Selected Cancers	Localized	Regional	Distant
Breast	98.9%	85.7%	28.1%
Esophageal	47.1%	25.2%	4.9%
Kidney	92.5%	68.3%	12.9%
Liver / Bile Duct	34.2%	12.0%	2.5%
Lung	64.1%	35.7%	7.1%
Ovarian	92.6%	74.8%	30.2%
Pancreatic	39.4%	13.3%	2.9%
Stomach	69.5%	32.0%	5.5%

Source: Surveillance, Epidemiology, and End Results Program (SEER) and National Program of Cancer Registries (NPCR) data, 2010 - 2016

## Late-Stage Diagnosis of Unscreened Cancer: a Health Disparity

In cancers without existing screening options, the prognosis is sadly much worse with later stage diagnoses. In pancreatic cancer, one of the top 10 leading causes of cancer deaths in the US, 5-year survival rates declined sharply between those diagnosed with localized versus distant cancer, from 39% to 2.9%, which is particularly troubling as just 10.8% of patients were diagnosed with local cancer compared to nearly half being diagnosed with distant cancer (Figure 3).<sup>29</sup> Similarly, the survival rate for late-stage kidney cancer diagnoses is 7 times lower for late versus early stage diagnoses.<sup>30</sup>

**Figure 3. Early-Stage Pancreatic Cancer Patients Have Better Survival Outcomes Compared to Later Stage Patients, but Almost Half of Patients Are Diagnosed at Distant Stages**



Source: Surveillance, Epidemiology, and End Results Program (SEER) and National Program of Cancer Registries (NPCR) data.  
Note: Five-year survival data references the period between 2010-2016. Percent diagnosed references the period between 2008-2017.

The relative survival rates between distant, regional, and localized cancer highlight the importance of early diagnosis for unscreened cancers without comprehensive guidelines for early detection efforts, as survival rates improve as the diagnoses shift from late to earlier stages.

**The negative impact of later-stage diagnoses is more prominent in racial and ethnic minorities.** Across many forms of cancer, racial and ethnic minorities often experience worsened mortality and survival outcomes compared to their NHW counterparts, overall and across stages of the disease. For example, data show that in liver and stomach cancers, 5-year mortality rates were higher among AI/AN, Asian/Pacific Islander, and Black individuals compared to NHWs.<sup>31,32</sup> In the case of kidney cancer, 5-year mortality rates were much higher in AI/AN populations compared to NHWs (5.5 per 100,000 vs. 3.8 per 100,000 in NHWs). Additionally, across other cancers, mortality rates were often higher for minority patients compared to NHWs (Table B).<sup>33</sup>

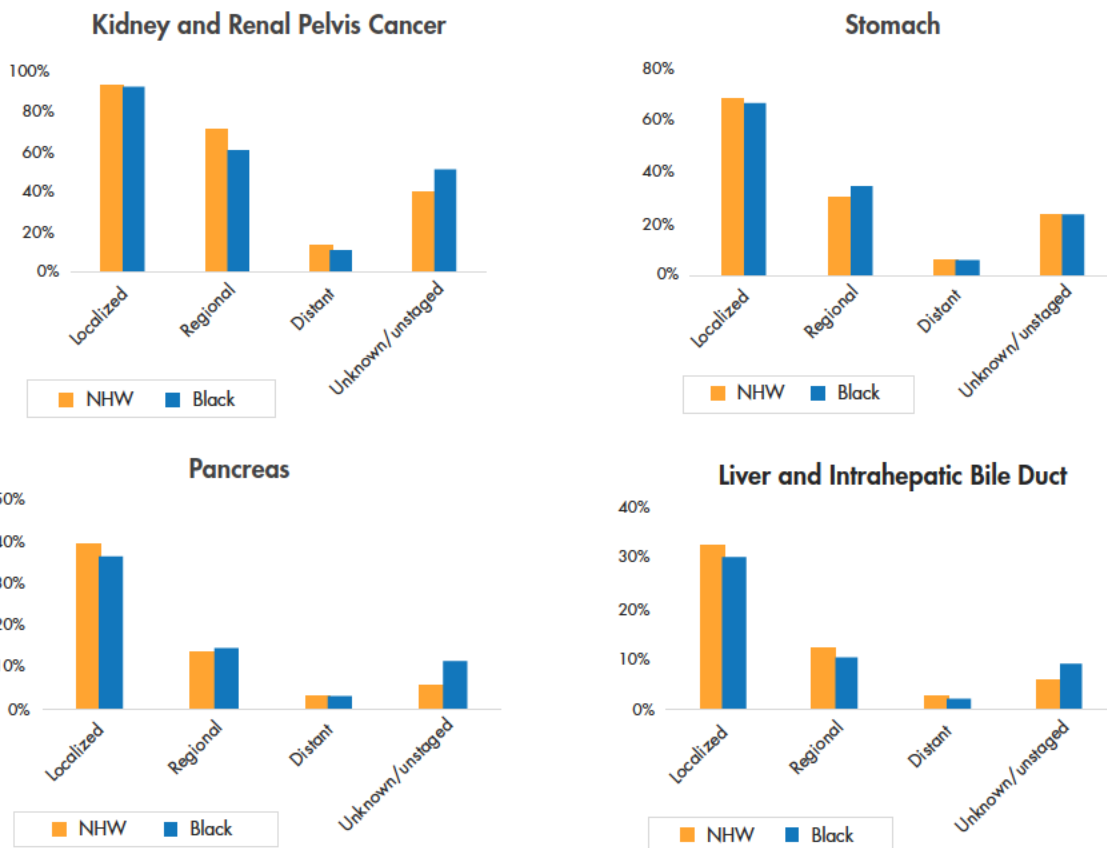
Data illustrate that, for Black Americans, outcomes in serious forms of cancer not only decline with later stages of diagnosis but are notably worsened compared to their NHW counterparts (Figure 4). For example, while the 5-year relative survival in kidney cancer declined sharply overall as diagnoses shifted to later-stage, the rates were different between NHW and Black Americans, shifting from 92.9% and 91.8% in localized cancer for NHW and Black Americans, respectively, to just 12.7% and 10.8% in distant-stage diagnoses.<sup>34</sup> While many factors may impact these disparate outcomes by stage, data show that racial and ethnic minorities are more often diagnosed with cancer at later stages than their NHW counterparts, which significantly contributes to these outcomes.<sup>35</sup> Shifting diagnoses earlier would have a particularly pronounced impact on improving outcomes for minority patients.

**Table B. Death Rates for Racial and Ethnic Minority Patients Are Higher Compared to NHWs Across Many Cancers Types, 2013-2017\***

Cancer Type	Black	AI/AN	Hispanic	NHW
Breast (female)	27.6	14.6	14.0	20.3
Esophageal	4.2	3.4	2.0	4.4
Kidney	3.6	5.5	3.5	3.8
Liver / Bile Duct	8.4	10.6	9.3	5.8
Lung	42.3	33.4	17.6	43.4
Ovarian (female)	6.0	6.3	5.2	7.3
Pancreatic	13.3	8.9	8.5	11.1
Stomach	5.3	4.8	5.0	2.3

Source: SEER. US and SEER Death Rates by Primary Cancer Site and Race/Ethnicity, 2013-2017, \*US Mortality Files, National Center for Health Statistics, Centers for Disease Control and Prevention. Rates are per 100,000 and are age-adjusted to the 2000 US Std Population (19 age groups - Census P25-1130). Both sexes included. [https://seer.cancer.gov/csr/1975\\_2017/results\\_single/sect\\_01\\_table.20\\_2pgs.pdf](https://seer.cancer.gov/csr/1975_2017/results_single/sect_01_table.20_2pgs.pdf).

**Figure 4. Five-Year Relative Survival Rates for Select Cancers by Race and Stage, 2010-2016**



## Spotlight on Screening

Current cancer screenings have been among the most important advances in the war on cancer. Detecting cancer early, before it has spread throughout the body, saves lives. Because treatment is more effective when cancer is detected early, existing screenings such as mammograms, colonoscopies, and pap smears have led to a substantial reduction in cancer mortality.<sup>36,37,38</sup> However, recommended screenings available today detect only 5 cancers - breast, cervical, colorectal, lung, and prostate cancer - meaning there are no screenings for most cancers. In fact, over 70% of the 600,000 cancer deaths each year are from cancers without early detection tests.<sup>39,40</sup>

Uptake of and adherence to recommended screenings varies significantly for the 5 available single-cancer screenings available today.<sup>41</sup> For example, adherence to recommended lung cancer screening is very low, with the ACS reporting that from 2016-2018, only 5%-6% of eligible adults received a recommended lung cancer screening.<sup>42</sup> There are a range of factors that may contribute to lower overall utilization of recommended screenings, including the interplay of social determinants of health, geographical or distance barriers, and a lack of health insurance or paid medical leave.<sup>43</sup> Underutilization of guideline-recommended screenings is often worse for many ethnic and racial minorities, compared to NHW, potentially contributing to disparities in cancer care and outcomes.<sup>44</sup>

It is also worth noting that some guidelines do not consider racial and ethnic disparities in risk. For example, a recent official statement from the American Thoracic Society noted that existing United States Preventive Services Task Force (USPSTF) lung cancer screening guidelines “do not consider racial, ethnic, socioeconomic, and sex-based differences in smoking behaviors or lung cancer risk.”<sup>45</sup> USPSTF recently updated its lung cancer screening recommendations to lower the age of screening and reflect smoking history, which was an important step in broadening the reach of the guidelines.<sup>46</sup> However, the USPSTF recommendations do not address many of the fundamental barriers that might help to reduce inequities in access to lung cancer screening across racial and ethnic minorities and have led to calls from stakeholders for screening criteria and systematic approaches that are more tailored to minority communities.<sup>47</sup>

Despite improvements related to early detection, there is still progress to be made in increasing adherence and expanding the benefits and positive outcomes of these benefits. As stakeholders continue to address the importance of screening tools in early detection, outreach and policy proposals must focus on improving awareness and addressing inequities impacting the health of racial and ethnic minority groups. Developing more targeted guidelines and recommendations that address the unique barriers facing these populations will be key. Strategies should also look to increase health literacy and utilize culturally-tailored educational and communication efforts that can be leveraged by trusted patient advocates in the community.<sup>48</sup>



### Policy Recommendations

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While there are many systemic barriers to address in working to eliminate inequities in cancer care, opportunities exist to focus on improvements in screening availability and utilization of early detection tools to increase the cancer detection rate (CDR) to diagnose and treat cancers at earlier stages and help improve outcomes for all cancer patients.

Cancer risk-reduction efforts should incorporate policy solutions and data-driven approaches that prioritize addressing systemic barriers to cancer screening and services across racial and ethnic minority groups. Progress to close gaps in cancer care between racial groups relies on key stakeholders, including patients, providers, researchers, diagnostic companies, advocacy groups, policymakers, regulators, federally funded organizations, and payers.<sup>49</sup>

The evolution of cancer early detection and risk-reduction efforts to reduce ongoing disparities in outcomes across racial and ethnic minority groups requires targeted actions and policy changes that support the needs of all patients, which can include:

1. Developing guidelines and recommendations for early cancer detection and screening that keep pace with rapid technological advancements and reflect the unique needs of minority and disadvantaged populations;
2. Creating incentives that drive continued innovation in early detection and screening technologies;
3. Ensuring coverage of and access to early detection and screening technologies in both private and public insurance plans covering underserved communities;
4. Developing better measures and standards for assessing impact of early detection and screening in minority communities, including the cancer detection rate, as well as the effectiveness and impact of policy changes, and;
5. Supporting broad initiatives that promote community outreach and education.

## Appendix

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### Methodology

This review examined how current gaps in cancer screening, due to the absence of clinical tools and guidelines, are impacting cancer detection, stage at diagnosis, and outcomes, specifically mortality. Our research focuses on how these gaps play a role in or drive cancer disparities among racial and ethnic minority groups across the United States.

The research includes a targeted review of both white and grey literature, and assessment of publicly available data from NCI's SEER Program and the CDC's US Cancer Statistics (USCS) databases.<sup>50,51</sup> We highlighted cancer types with known gaps or opportunities for improvement in screening or early detection. Specifically, we focus on cancer types without any methods or consensus-based recommendations (i.e., from professional societies or recommending bodies like the USPSTF) for routine screening. We refer to these cancers as "unscreened cancers."

For the review, we narrowed the list of cancers to pancreatic, stomach, esophageal, kidney (renal cell and renal pelvis), ovary, and cholangiocarcinoma.

From both our white/grey literature search and review of publicly available SEER and USCS data, we selected summary statistics and cancer-type specific profiles on incidence rates, stage of diagnosis, and mortality rates across racial and ethnic minority groups as well as geographic location. From both the SEER and USCS databases, our research pulled data outputs to examine incidence rates, stage of diagnosis, and mortality rates as they relate to survival rates by racial and ethnic minority groups, as well as across geography for the above unscreened and under-screened cancer types. In review of available data outputs for the above unscreened cancer types, the summary statistics and graphics included in the paper underscore prime examples where cancer type-specific disparities exist in early detection efforts across racial/ethnic minority groups.

The National Minority Quality Forum (NMQF) seeks to explore the current landscape of data on cancer disparities that exist among racial and ethnic minority groups in the US and assess the impact of early cancer diagnoses and detection. Avalere, a public policy and business strategy consultancy in Washington, DC, conducted a literature search and extracted data from the SEER and USCS databases. The findings from this research could support efforts to increase awareness of cancer disparities and may be used to inform policy recommendations aimed at advancing cancer reduction efforts and improving cancer health outcomes. This research was sponsored by GRAIL.

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