



# Advancing Health Equity with Charitable Copay Assistance

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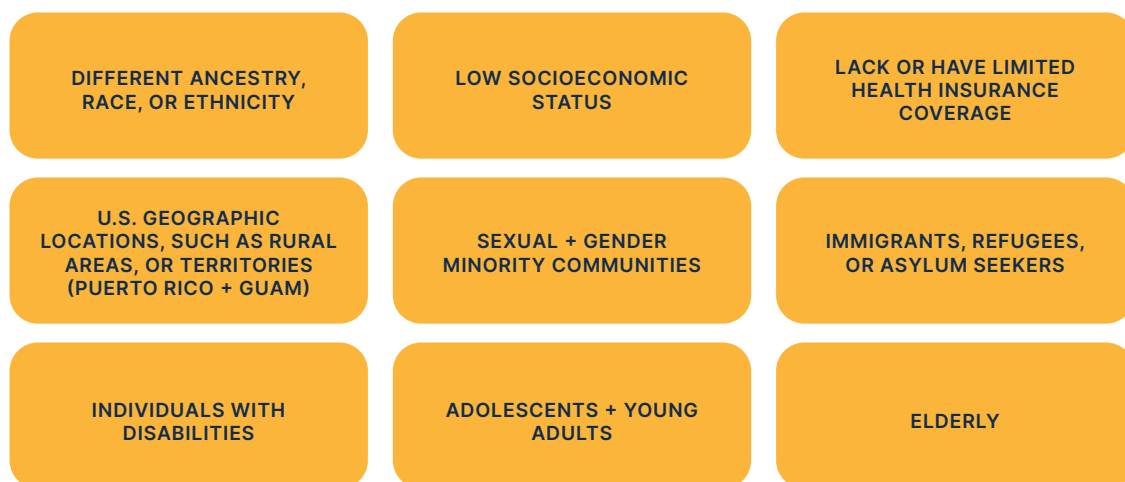
# Background

An important reason to focus on elevating cancer health equity is that advances in cancer care and treatments have improved the quality of care but may not be accessible to all individuals. Cancer health disparities are the difference in cancer measures such as cancer incidence, deaths, complications, survivorship and quality of life, screening rates and stage of diagnosis that exist among certain populations. Well documented cancer health disparities persist for members of racial and ethnic communities, individuals with limited English proficiency, and individuals with low health literacy. Additionally, socioeconomic inequities in cancer mortality have widened over the past three decades. Racial and ethnic minorities tend to receive lower quality healthcare than Non-Hispanic Whites. For example, Black patients have the highest death rate and shortest survival of any racial/ethnic group in the U.S. for most cancers. **See Figure 1.**

FIGURE 1

## Which U.S. Population Groups Experience Cancer Health Disparities?

According to the National Cancer Institute, cancer health disparities in the U.S. are adverse differences in cancer measures such as number of new cases, number of deaths, cancer-related health complications, survivorship and quality of life after cancer treatment, screening rates, and stage at diagnosis that exist among certain population groups including:



It is important to note that some populations may carry even a higher burden of cancer because they simultaneously fall into more than one of these categories.

## Impact of Financial Toxicity

Another reason to advance health equity is the opportunity to reduce financial toxicity. The same population of individuals experiencing cancer healthcare disparities are also at a greater risk for financial toxicity. Financial toxicity describes financial hardships and strain that patients experience related to the cost of treatment and care. Financial toxicity is the unintended, but not necessarily unanticipated, objective financial burden and subjective financial distress experienced by cancer patients because of their treatment costs.

- Objective financial burden describes the direct out-of-pocket costs for medical care and the non-medical costs such as transportation, housing, food, and childcare.
- Subjective financial burden results from the accumulation of the out-of-pocket expenses over the time from diagnosis, reduction of personal assets, and the coping strategies used by the patients and families.

Often, guideline-adherent multidisciplinary cancer care includes surgery, oral and/or intravenous administered (systemic) therapies, and radiation therapy. 22 to 50% of cancer patients who receive systemic therapy, radiation therapy, surgery, or participate in a clinical trial reported financial distress. Financial toxicity has been linked to several clinically relevant patient outcomes such as quality of life, symptom burden, compliance, and survival.

However, there are many ways that patients can get philanthropic medical aid to cover high-cost treatments. Drug manufacturers (life science companies) and charitable foundations provide financial programs for patients facing out-of-pocket costs associated with high-cost therapeutic drugs. Charitable foundations also provide support grants to help patients pay for costs such as health insurance premiums, clinical trial participation, transportation, housing, food, utilities, and childcare.

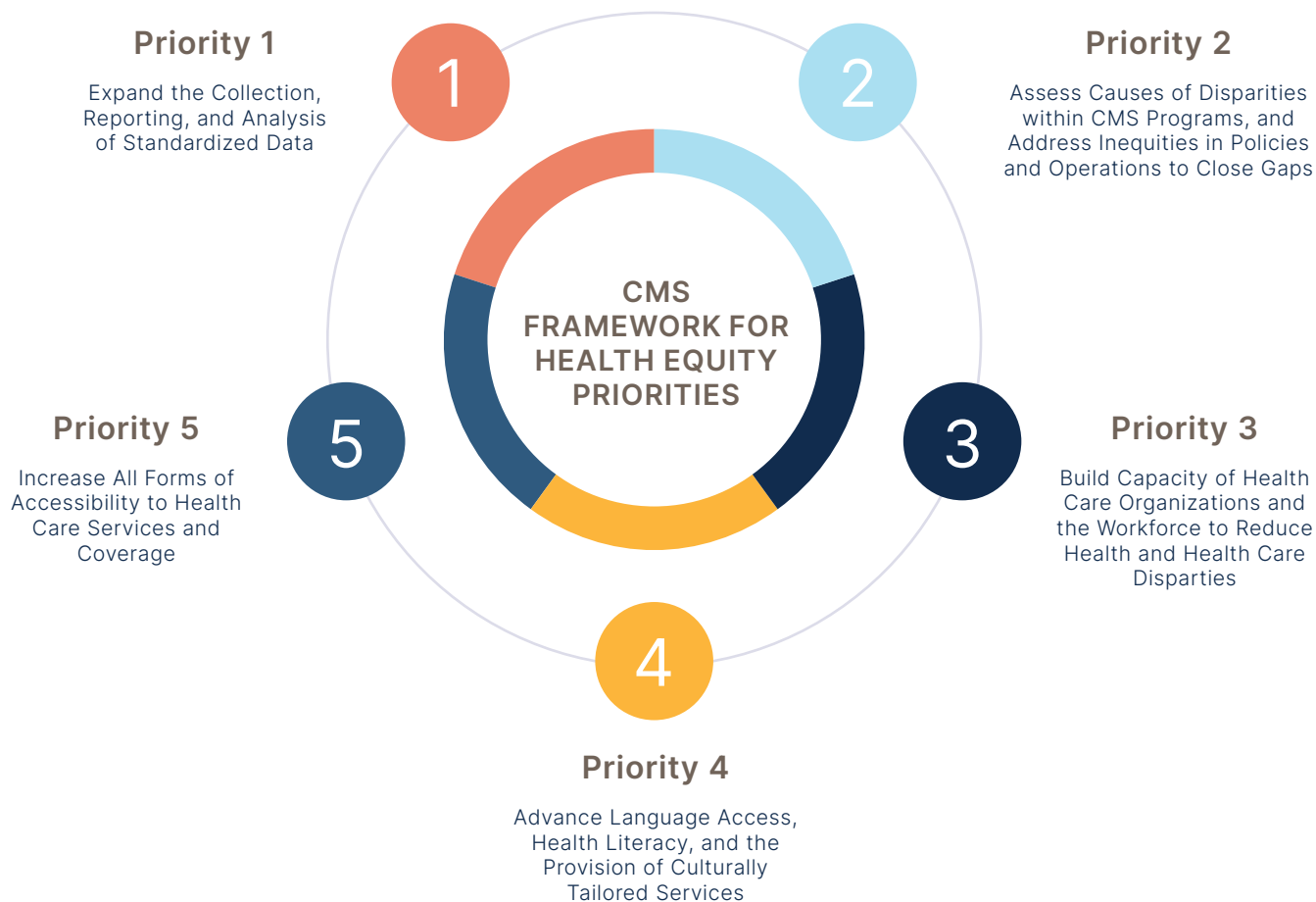
In a 2022 American Cancer Society Cancer Action Network survey, of the 1,241 patients across the U.S. that were treated for cancer, one-third reported that prescription drug costs were a challenge. One-fifth reported having skipped or delayed taking a prescribed medication due to difficulty paying the cost. Significantly higher rates of missed medication were reported by patients with lower income or individuals representing racial/ethnic minorities.

Additionally, many hospitals and health systems provide patients access to copay assistance programs via financial navigators or financial counselors. Performance is often measured based on productivity, access, and financial metrics to illustrate the economic benefit or return on investment of the program. For example, Cleveland Clinic's Financial Navigation Program metrics include the percentage of all infusion treatment patients reached by financial navigators, copay assistance program applications filed, copay assistance program applications approved, aggregate dollars applied/dollars received, total dollar amount of approved applications for free drug, average total dollar amount per application, and the time in days from patients' first positive biopsy to first treatment. Little is known about the sociodemographic characteristics of the patients receiving copay assistance or those left behind. Program metrics that measure reduction in healthcare disparities are not widely understood. By applying the CMS Framework for Health Equity to clinical outcomes reported in a published national survey and data from a national charitable foundation, this paper will identify opportunities to uncover healthcare disparities as a way forward for copay assistance programs to elevate health equity.

# Methods

Copay assistance programs' current state design may not reduce healthcare disparities without a new structured approach. The [CMS Framework for Health Equity](#) was designed to help organizations achieve health equity and reduce disparities among minority and underserved populations. Since most cancer patients are Medicare eligible and charitable foundations serve mainly Medicare recipients, this framework is a good fit. The CMS Framework for Health Equity outlines five priorities which provide an integrated approach to build health equity into existing and new efforts by CMS and its stakeholders. Based on the funds considered here, 92% of HealthWell's grant recipients are Medicare eligible, age 65+; additional sociodemographic data of copay assistance recipients will be needed based on the recommendations in this framework. **See Figure 2.**

FIGURE 2



# HealthWell Foundation Cross-Sectional Survey and Cancer Disease Funds

## METHODOLOGY

Current published research illustrates some of the sociodemographic data for cancer patients receiving copay financial assistance. Dr. Jeffrey Peppercorn, Director Supportive Care and Survivorship for Massachusetts General Hospital Cancer Center and authors representing organizations including Fox Chase Cancer Center, Temple University Health Systems, University of North Carolina, and University of Oklahoma conducted a national, cross-sectional survey of copay financial assistance recipients from HealthWell Foundation. [HealthWell Foundation](#) is a leading independent non-profit dedicated to improving access to health care for America's uninsured. HealthWell Foundation assists patients with copays, premiums, deductibles.

1,108 recipients of copay assistance grants (financial assistance) from HealthWell Foundation were surveyed represented patients with:

- ✓ over 20 different cancer types (30% solid tumors and 70% hematologic malignancies)
- ✓ average age of 72 years old
- ✓ 60% male
- ✓ 88% Non-Hispanic White
- ✓ 55% college educated
- ✓ 67% had annual income < \$60K
- ✓ 96% had Medicare Coverage
  - 53% had traditional Fee for Service Medicare
    - 58% had Medicare Part A and Part B with Supplemental insurance.
    - 43% had a Medicare Advantage plan

## Results

The primary outcome of interest was patient self-reported financial distress using the Comprehensive Score for Financial Toxicity (COST). Secondary outcomes included measures of out-of-pocket spending, perspectives on copay assistance, healthcare access and costs, and the impact of financial burden on healthcare utilization.

**56%** reported mild and 27% reported moderate/severe financial toxicity. Traditional fee for service Medicare insurance was significantly associated with greater financial distress.

**18%** reported skipping medical services due to cost.

**17%** reported delays in starting therapy due to cost with over 1 in 4 patients experiencing delays beyond 4 weeks.

**54%** reported spending greater than \$500 per month on healthcare with 39% spending greater than 10% of their household income.

**24%** believed they would not have received treatment without financial assistance.

**73%** reported a decrease in financial concerns because of receiving patient copay assistance.

# Comparison with HealthWell Foundation Cancer Disease Funds

Published research data alone will not identify health disparities and elevate health equity as research participants may not represent all patient populations. The findings from the cross-sectional survey were compared to the sociodemographic data of grant recipients of HealthWell Foundation’s cancer disease funds for 2021 and 2022. HealthWell Foundation has 39 cancer (oncologic/hematologic malignancies) disease funds of which 33 are defined by primary diagnoses and 6 are by secondary (supportive care) diagnoses. Of the primary cancer disease funds, one-third are for patients with hematologic malignancies and two-thirds for solid tumors. 46% of the cancer disease funds are available to Medicare insured patients only. **See Figure 3.**

FIGURE 3

Disease Fund Name	Solid Tumor or Hematologic Malignancy	Medicare Access Only	Primary Diagnosis	Secondary Diagnosis
Acute Myeloid Leukemia	H	Y	Y	
B-Cell Lymphoma	H	Y	Y	
Bladder Urothelia	S	Y	Y	
Bone Metastasis		Y		Y
Break Through Cancer Pain		Y		Y
Breast Cancer	S	N	Y	
Cancer Related Behavior Health		N		Y
Carcinoid Tumors	S	N	Y	
Chemotherapy Induced Anemia		N		Y
Chemotherapy Induced Neutropenia		Y		Y
Chemotherapy Induced Nausea/Vomiting		N		Y
Chronic Lymphocytic Leukemia	H	N	Y	
Chronic Myelogenous Leukemia	H	N	Y	
Colorectal Cancer	S	Y	Y	
Cutaneous T-Cell Lymphoma	H	N	Y	
Gastric Cancer	S	Y	Y	
Glioblastoma	S	N	Y	
Head & Neck Cancer	S	Y	Y	
Hepatocellular (Liver)	S	Y	Y	
Hodgkins Lymphoma	H	N	Y	
Mantle Cell Lymphoma	H	N	Y	
Melanoma (Skin)	S	N	Y	
Multiple Myeloma	H	Y	Y	
Myelodysplastic Syndrome	H	Y	Y	
Non-Hodgkins Lymphoma	H	Y	Y	
Non-Small Cell Lung Cancer	S	N	Y	
Ovarian	S	Y	Y	
Pancreatic	S	Y	Y	
Prostate	S	Y	Y	
Renal Cell (Kidney)	S	Y	Y	
Small Cell Lung Cancer	S	Y	Y	
Waldenstrom’s Macroglobulinemia	H		Y	
Wilms Tumor	S		Y	

The number of approved grants for cancer patients in 2021 was 68,677 which decreased 5% to 65,243 in 2022. The total dollar value of grants paid was \$352M in 2021 and decreased 8% to \$324M in 2022. The average grant amount paid was \$5,125 in 2021 and \$4,968 in 2022. While all disease fund recipient locations were different, the most common top three states where grant recipients resided were Florida, Texas, and California. 99% of the grant types were copay assistance and 1% were health insurance premiums.

For 2021 and 2022 combined, the age distribution of the grant recipients was 92% age 65+, 7% age 50-64, 1% age 35-49, and 0% age under 35 and 63% were male, 37% female. Family income for grant recipients across all funds was reported as a percentage of the Federal Poverty Level (%FPL). Eligibility for most programs requires family income to be below 400 to 500% FPL. For example, in 2021, the largest percentage of grant recipients, 21%, family income measures at 150 to 200% FPL, second largest, 19.7%, at 100 to 150% FPL, and third largest, 17.2%, at 200 to 250 % FPL. **See Figure 4.** In the current state, HealthWell does not capture grant applicants' sociodemographic data such as educational level attained, race, ethnicity, preferred language, sexual orientation, gender identification, disability status, or other social determinants of health (SDoH).

**2021-2022  
Distribution of Grant Recipients**

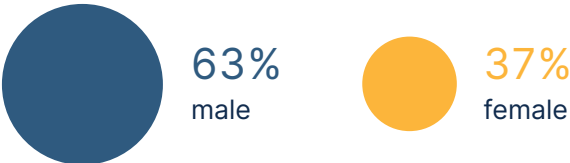
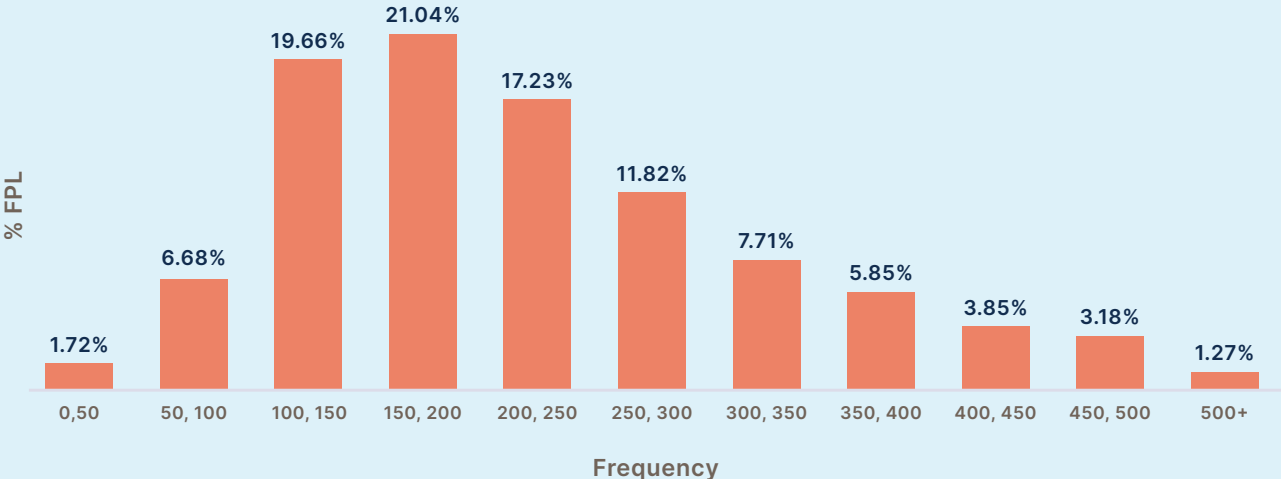


FIGURE 4

**2021 FPL Distribution - All Funds**



## PATIENT ACCESS TO HEALTHWELL'S DISEASE-BASED PROGRAMS

Accurate referral data is essential to determine potential healthcare disparities. Data from 2021 and 2022 was reviewed to determine how patients access HealthWell's copay assistance programs. In 2021 and 2022, over two-thirds of patients, 124,074 and 123,710 patients respectively, were referred to HealthWell via their portal where applications were completed on the patients' behalf effectively reducing barriers to access. For 2021 and 2022, the remaining one-third of patients, 61,416 and 59,858 respectively, were directed to HealthWells's website or hotline number to self-enroll. For example, in 2022, the largest referral sources for patients' self-enrollment were pharmacies (17,091), providers, nurses, and advocates (16,279), other (7,485), drug manufacturer reimbursement support line (5,710), and copay assistance program sponsored by another foundation (4,765). Percentages for each referral source do not match the HealthWell website data as the "Referral Source, Other" does not include blanks, not applicable, unsure, not provided. *See Figure 5.*

FIGURE 5

Referral Sources	2021	%	2022	%
Another Copay Foundation (Patient Assistance Program)	5,076	8.26%	4,765	7.96%
Case Manager/Social Worker	2,807	4.57%	2,272	3.80%
Disease-Specific Non-Profit/Patient Support Organization	1,738	2.83%	1,152	1.92%
Financial Counselor	722	1.18%	716	1.20%
Media/Social Media	158	0.26%	140	0.23%
Other (Including Blanks, Not Applicable, Not Provided and Unsure)	8,152	13.27%	7,485	12.50%
Patient/Family Member/Caregiver	1,673	2.72%	2,179	3.64%
Pharmacy	18,384	29.93%	17,091	28.55%
Private Insurer (e.g. BCBS, United)	725	1.18%	546	0.91%
Provider/Physician/Nurse/Advocate	14,822	24.13%	16,279	27.20%
Public Insurer (Medicare, Medicaid)	378	0.62%	377	0.63%
Reimbursement Support Line/Manufacturer	5,534	9.01%	5,710	9.54%
Website/Web Search	1,247	2.03%	1,146	1.91%
<b>Total</b>	<b>61,416</b>		<b>59,858</b>	
<b>Grant Enrollment by Provider (Portal)</b>				
Provider Portal	124,074		123,710	
<b>Grand Total</b>	<b>185,490</b>		<b>183,568</b>	



Language can be a barrier to accessing copay assistance programs. Language contributes to patients’ health literacy level which impacts self-enrollment ability via the hotline and the website. In current state, the HealthWell website content is available in English. For Spanish speaking individuals, there is an Espanol tab in the home webpage and Solcitar tab in the application section which displays the instructions and application in Spanish. A small number of patients requested translation services when using the HealthWell hotline, 270 in 2021 and 222 in 2022. When patients requested interpreter services, Spanish was used 96% of the time for phone encounters. **See Figure 6.**

FIGURE 6

**Language Used While Applying For A Grant Through Our Hotline**

Language Used	2021	2022
Spanish	238	190
Other Languages	32	32

**Ranking Of Languages Used When Patients Were Connected To Our Third Party Language Line**

Time Frame: March 2022 - May 2023

Language	Use of Language Line (#)	Use of Language Line (%)
Spanish	1,670	95.7%
Korean	13	0.74%
Mandarin	10	0.57%
Vietnamese	8	0.46%
Cantonese	6	0.34%
Russian	6	0.34%

## OPPORTUNITY FOR LINKAGE BETWEEN THE TOTAL GRANT AMOUNTS AND PREVALENT DISEASES FOR RACIAL/ETHNIC MINORITIES

The value of philanthropic donations contributed to each Health Well disease-based fund determines the total dollars available per year and the number of approved grants per fund. The average grant paid amount is determined by the actual paid awards by year. Currently, life science companies are the largest donor source. As we apply the CMS Framework for Health equity to copay assistance programs, expanding the number of diagnosis-based funds and increasing the total value of diagnosis-based funds using cancer prevalence for racial and ethnic minorities as the criteria will expand access for more patients and families.

To reduce healthcare disparities, disease-based funds for patient populations with the highest incidence of cancer would have the highest total grant amounts. The 2022 total grant amount, approved number of grants, and average grant amount per patient for each diagnosis-based fund were compared to new cancer cases and the National Cancer Institute (NCI) 5-year survival rates for overall population. The NCI 5-year survival rate is the percentage indicating the proportion of people with a particular cancer diagnosis that are likely to be alive after 5 years. Besides the prostate cancer disease-based fund, the amount of funds available do not match the diseases with the highest prevalence for all populations and specifically for Black and Hispanic men and women. The breast cancer disease-based fund of \$7.9M is surprisingly small given that breast cancer has a 90.3% 5-year survival rate and is the most prevalent cancer in women across all populations. For Black and Hispanic women, breast cancer has a higher prevalence, but significantly greater mortality when compared to White women.



The three disease-based funds with the largest total grant value distributed in 2022 were prostate cancer at \$47M, kidney cancer at \$45M, and Leukemia at \$27.4M. Only the prostate cancer disease-based fund represents the top three cancers by incidence (breast, prostate, and lung) or the top five cancers with the highest 5-year survival rates (thyroid, prostate, melanoma, breast, and uterine). A greater gap is illustrated when we compare diagnosis-based funds with the top ranked cancer incidence for Black and Hispanic men and women. For Black men, prostate, lung, and colorectal cancers are the top three in terms of incidence with only the prostate cancer fund being one of the largest disease-based funds. Despite being the second and third most prevalent cancer for Black men, the lung and colorectal cancer disease-based funds were small with lung at \$4.7M and colorectal cancer at \$600K. There were no available funds for uterine cancer and thyroid cancer diagnosis-based funds even though these diagnoses represented the 2nd and 3rd most prevalent cancers for Hispanic women. Data representing these gaps would be useful to identify new philanthropic sources and health equity grants for oversubscribed and missing disease-based funds. *See Figure 7.*

FIGURE 7

Cancer Type	New Cancer Prevalence-all population	Top ranked diagnosed cancer type- Black Men	Top ranked diagnosed cancer type- Black Women	Top ranked diagnosed cancer type- Hispanic Men	Top ranked diagnosed cancer type- Hispanic Women	New Cases 2021	%	NCI 5 year Survival	2022 Total Grant	2022 Approved Grants	2022 Avg Grant
Breast	1		1		1	284,200	14.8%	90.3%	\$ 7.9 M	1,764	\$4,525
Prostate	2	1		1		248,530	13.1%	97.5%	\$ 47 M	14,306	\$3,291
Lung	3	2	2	3		235,760	12.4%	21.7%	\$ 4.7 M	1,900	\$2,498
Colonrectal	4	3	3	2	2	149,500	7.9%	64.7%	\$ .6 M	279	\$2,132
Melanoma	5					106,110	5.6%	93.3%	\$ 4.1 M	651	\$6,371
Bladder	6					83,730	4.4%	77.1%	\$ 0 M	484	\$1,754
NHL	7					81,560	4.3%	73.2%	\$ 0 M	0	\$-
Kidney	8					76,080	4.0%	75.6%	\$ 45 M	7,949	\$6,054
Endometrial (uterine)	9				2	66,570	3.5%	81.1%	\$ 0 M	0	\$-
Leukemia (all types)	10					61,090	3.2%	65.0%	\$ 27.4 M	5,767	\$4,967
Pancreatic	11					60,430	3.2%	10.8%	\$ 0.71 M	467	\$1,522
Thyroid	12				3	44,280	2.3%	98.3%	\$ 0 M	0	\$-
Liver	13					42,230	2.2%	20.3%	\$ 0 M	0	\$-

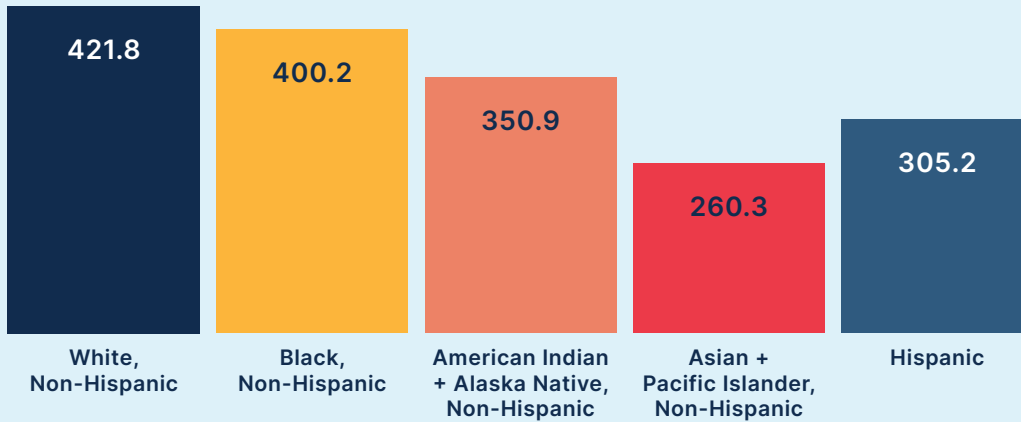
Advancing health equity presents a compelling reason to look at data collection and analysis through a new lens. Given social drivers affecting cancer outcomes and program elements of copay assistance, the additional data for consideration would be race, ethnicity, preferred language, gender identity, sexual orientation, disability, and education level.

Collecting data on race, ethnicity, and preferred language for individuals applying for copay assistance is a crucial step to identify potential disparities and determine how to address them. When we compare the race and ethnicity composition of the participants in the “national survey of financial burdens and experience among patients with cancer receiving charitable copay assistance,” to the rate of new cancers in the U.S. by race and ethnicity, we see significant differences. First, the national survey included a small number of total grant recipients, 1,108, when compared to the total number of patients with approved HealthWell cancer grants, over 133,000 a year in 2021 and 2022. Secondly, 88% of survey participants were Non-Hispanic White individuals which is much higher than the 2020 rate per 100,000 people of new cancers for Non-Hispanic White men and women suggesting that Non-Hispanic White survey participants were disproportionately represented. **See Figure 8.**

FIGURE 8

## Rate of New Cancers by Race and Ethnicity, Both Sexes

All Types of Cancer (rate per 100,000 people)



### IMPACTS OF LOW HEALTH LITERACY

Health literacy is defined by the [U.S. Department of Health & Human Services \(HHS\)](#) as the degree to which individuals understand and use health related information and services. Individuals who do not speak English at home, immigrants, and individuals with lower levels of education are at a higher risk for having limited English language skills and low literacy. Having limited English proficiency can be a barrier to accessing healthcare services and limited literacy is a barrier to accessing health information. [Research](#) demonstrates that limited language skills and low literacy are associated with worse health outcomes. [One in six \(16%\)](#) cancer survivors report low health literacy. The prevalence of low health literacy was higher among Hispanic and Black cancer survivors and among those with lower educational attainment and household income.

Given that the impact of English proficiency and low health literacy on outcomes, the percentage of time that patients asked for a language interpreter service when using the Health Well telephone hotline was compared with the percentage of individuals in the U.S. that speak English as their primary language. The use of the interpreter service was less than 0.5%. In 2019, 21.6% of the U.S. population older than 5 years spoke a language other than English at home. This significant difference in percentages could suggest barriers to accessing copay assistance programs for non-English speaking patients.

Applying for a copay assistance grant requires patients to have a certain level of language skills and health literacy. The complexity of enrollment is mitigated when health care providers complete the enrollment process on behalf of patients using HealthWell's provider portal. In 2021 and 2022, the two largest referral sources of patients to the HealthWell hotline were from pharmacists/pharmacy technicians, 30%, and providers/physicians/nurses/advocates, 24%.

Historically, HealthWell has found that patients prefer to talk through the enrollment process with a specialist via the hotline. In fact, one-third of the total grant applicants self-enrolled via the hotline. In addition to the patient portal, HealthWell supports robust and continuously enhanced provider and pharmacy portals; increased use of the HealthWell portals by non-patient advocates like providers and pharmacies would support greater access to copay assistance with lower health literacy.

# Conclusion

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To implement best practices aligned with the CMS Framework for Health Equity, data collection for copay assistance grant applicants should include additional standardized data such as race, ethnicity, preferred language, gender identity, sexual orientation, and disability status. As we strive to ensure inclusive resources, charitable foundations will need to provide linguistically and culturally appropriate access to programs.

Future analysis needs to include a review of patients who applied for a copay assistance grant but were not eligible to identify if health disparities exist. Establishing processes and timing for obtaining additional data will be essential to ensure that the data requests do not create unintended enrollment barriers. Ongoing analysis using sociodemographic data of patients receiving resources and those that do not will help identify disparities in access to copay assistance programs, determine causes, build capacity, advance language access, health literacy, and provision of culturally tailored services to increase access to copay assistance for all eligible populations.

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