

Impact of Race and Gender on Allocation of Cancer Research Funding

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On my honor as a University Student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments

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Introduction

Cancer is currently the second most common cause of death in the United States, killing more than 600,000 people in 2022, with nearly 2 million new cases in the same period (*2022 Cancer Facts & Figures Cancer | Cancer Death Rate Drops*, n.d.). As such, the disease impacts a majority of Americans, whether directly or indirectly through the illness of a loved one.

However, certain types of cancer have higher incidences in certain populations due to external factors such as environmental exposures or participation in specific behaviors, or internal factors such as race and sex (*Risk Factors for Cancer - NCI*, 2015). For example, lung, colorectal, and gynecologic cancers disproportionately affect the Black population and certain cancers affect female sex organs such as ovarian, cervical, and endometrial cancers thus affecting more women (*Disparities Found in Funding of Cancer Research, 2022, Why Are Some Cancers Better Funded Than Others?*, 2019).

Research of cancer disease mechanisms, causes, and potential treatments is funded both publicly through the federal government and privately through non-profit organizations. Public funding comes from the National Institutes of Health (NIH), primarily through the National Cancer Institute (NCI), with a budget given by US Congress through the federal budget process. Recently, partially through Cancer Moonshot, an initiative reignited by the Biden Administration to more rapidly advance cancer research through collaboration, the NCI budget has increased to \$7.3 billion in 2023 (*About the Cancer MoonshotSM - NCI*, 2022, *NCI Budget and Appropriations - NCI*, 2015). In fiscal year 2021, 71.3% of the NCI budget went towards research including its own intramural research, widespread initiatives such as cancer centers, and investigator-initiated research grants, with 42.3% of the total budget going towards these grants (*NCI Budget Fact Book - NCI*, 2022). In contrast, non-profit organizations, the largest of which being the American

Cancer Society, is mainly funded by personal donations(*How American Cancer Society Research Funding Works*, n.d.). Similarly to the NCI, non-profit organizations both do their own research and provide grant funding to individual research proposals. In contrast, non-profit organizations can either provide general funding (the American Cancer Society) similar to the government, or the organization can focus on specific types of cancer.

Regardless of the funding source, all cancer research funding is primarily split up by the type of cancer being addressed. However, this shows the resulting disparities within research funding based on the type of cancer. Specifically, cancers that have higher incidence within Black populations and those associated with female sex organs receive disproportionately less funding than other types of cancer(*Disparities Found in Funding of Cancer Research*, 2022, *Why Are Some Cancers Better Funded Than Others?*, 2019, Samuelson, 2019, Spencer et al., 2019). These disparities occur both within public and private funding sources; however, non-profit organizations cannot be regulated to compensate for less favored cancer types in the same way federal funding can be. While the government cannot control the scientific discoveries involved in medical research and what types of cancers are easier to find treatments for, it can make funding for those research efforts more equitable for the populations being served. Moreover, federally funded programs cannot contribute to disparities based on sex and race according to Title VI of the Civil Rights Act of 1964(*Education and Title VI*, 2023). As such, I intend to research how policy can best solve this problem of funding disparities between races and sexes.

Background and Significance/Motivation

This research is important because no one deserves to have fewer options for care, less access to care, less effective treatments, and generally less consideration based on the social

factors surrounding their disease. Moreover, it has been shown that increased NCI funding correlates with increased survival rates(*NIH and NCI Funding for Pancreatic Cancer Research – Pancreatic Cancer Action Network*, n.d.). It is out of control of patients whether they are afflicted with a disease that is more common among Black populations, and/or associated with female sex and reproductive organs, thus these factors should not impact the investment in their chances for survival. The types of cancer that exemplify these disparities are colorectal, pancreatic, liver and bile duct, brain, lung, ovarian, cervical, and endometrial cancers. With current NCI funding distributions, these cancers have significantly lower funding per person-life years lost per 100 cases scores than prostate and breast cancer with colorectal at .442, brain/ONS at .110, ovary at .097, compared to prostate at 1.812, and breast at 1.803(Spencer et al., 2019).

The relevance of this research to the field of biomedical research revolves around the need for incorporating empathy and equity in research design. By addressing widespread disparities that affect the funding of research projects, the research itself can have a more significant impact on the target population.

Methodology

As the identified need has been for a policy solution, the best way to evaluate the current state of the issue and the merit of possible alternatives is a policy analysis. This involves a seven step structure based on Bardach's 'Eightfold Path to More Effective Problem Solving' as follows: define the problem, background evidence, present alternatives, select success indicators, describe project outcomes, confront tradeoffs, and recommendation(Bardach, 2012). This method was chosen to more accurately compare different solutions based on the specific goal of reducing funding disparities while continuing to consider the impacts of each potential policy alternative.

Moreover, as these solutions will be focused on addressing the issues within the federal government, funding from non-profit organizations will not be considered further.

This issue will also be evaluated within the framework of critical theory, both in terms of race and sex. Critical race theory (CRT) focuses on how racism functions and impacts people on individual and widespread levels, and gives a means for identification of the behaviors of racism on a systemic level(Graham et al., 2011). Critical theory can be applied to biological sex in much the same way, focusing on how sex and sexism impacts the individual and society. In this particular case, this framework allows the racism and sexism within the federal government's cancer research funding structure to be acknowledged and the structure to be examined with regards to race, sex, and privilege.

Literature Review

Current Funding Structure

Along with the NCI, federally funded cancer research also occurs in other federal agencies including: the Food and Drug Administration (FDA), the Center for Disease Control and Prevention (CDC), the Department of Defense (DoD), the Environmental Protection Agency (EPA), as well as other programs within the Department of Health and Human Services (HHS). Funding from these sources comes in multiple different forms including development of internal research, funding of external research projects through grant applications, and regulation and review of existing treatments and medical devices. Research funding is also broken down by type of cancer; however, as NCI is the largest funding source it has the most comprehensive available data on the funding distribution by cancer type. Decisions for grant applications are made by NCI Scientific Program Leaders, with “scientific merit ... the primary consideration in these funding decisions” and “additional efforts to support early career investigators”(NCI

Funding Policy for RPG Awards, n.d.). For the most part, what types of projects get funded is influenced by human decision making, both by the research community via which projects are proposed for grants and by the NCI leadership deciding what grants get approved.

Of the \$6.35 billion NCI fiscal year 2021 budget, 71.3% went to research funding and 42.3% of the overall budget was allocated specifically for research project grants(*NCI Budget Fact Book - NCI, 2022, 2021 NCI Budget Fact Book - Funding for NCI Program Areas - NCI, 2022*). According to the most recent data available, actual spending from 2018 and projected spending from 2019 and 2020, breast cancer is by far the highest funded research category- apart from clinical trials which includes projects applying to many types of cancer- with \$574.9 million spent in 2018. In contrast, colorectal, ovarian, and uterine cancers each received 256.0, 120.8, and 17.5 million dollars respectively, in the same time period(*2021 NCI Budget Fact Book - Research Funding - NCI, 2022*). From 2015-2020, the range of spending per cancer type (not including clinical trials) between the highest and lowest funded type has varied between \$507.1 and \$584.6 million with no clear trend. However, the standard deviation, a more descriptive indicator of the distribution of this funding, has increased from \$124.8 million in 2016 to a projected \$165.1 million in 2020, as seen in Table 1(*2021 NCI Budget Fact Book - Research Funding - NCI, 2022*).

	2015	2016	2017	2018	Est 2019	Est 2020
Range	530.6	507.1	531.9	561.6	533.2	584.5
Standard Deviation	128.4	124.8	130.8	137.4	135.9	165.1

Table 1- Calculated range and standard deviation of NCI funding between types of cancer (*2021 NCI Budget Fact Book - Research Funding - NCI, 2022*)

Why These Disparities Exist?

Currently, cancer research funded by the NCI has a strong positive correlation between incidence and funding, so it makes sense that more common cancers such as breast cancer

receive higher funding than less common cancers such as colorectal and uterine cancers(*Disparities Found in Funding of Cancer Research*, 2022). While this standard aims to increase the impact of research by expanding the number of people the results of the research could affect, the result is that Black and female populations are subjected to disproportionately lower research funding. One possible reason for this disparity could be the personal bias of those approving the grants. Rather than providing research funding to populations based on intensity of need, such as the fatality of a cancer or the current state of treatment research, NCI leadership could be approving research grants and internal research based on how many individuals are experiencing any amount of need. This approach would compound with leadership biases in the form of the lack of consideration for the treatment of these marginalized communities. Another possible reason for this disparity could be the biases of the researchers proposing for NCI grants or internal NCI research. In this case the scientists themselves focus their own research on more common cancers, skewing the applicant pool towards these types of cancer. It is possible that these two factors contribute to each other meaning researchers are aware of which cancers receive more funding, so they pursue research in those areas, and cancer researchers are proposing significantly more projects for common cancers leading NCI leadership to have more scientifically viable options relating to those types of cancer.

Policy Alternatives

Regardless of possible reasons for these disparities, whether one or both of those listed above or another one not previously considered, one or more solutions need to be considered to prevent this from continuing. I propose four possible policy alternatives to act as solutions for this problem, the first of which is the current policy strategy. This strategy would continue the current funding allocation processes of the NCI, thus the factors considered would remain

scientific merit, emphasis on support for early investigators, and likely the incidence rate of the type of cancer being studied as previously described.

The next proposed policy alternative is an algorithm that would be developed for use by NCI leadership during the funding appropriation process in an attempt to more equitably distribute funding. This algorithm, based on a proposal by Dr. Suneel Kamath of the Cleveland Clinic Taussig Cancer Center, would consider factors such as incidence along with fatality and population most affected by the cancer at the focus of the given project (*Disparities Found in Funding of Cancer Research*, 2022). Use of an algorithm would attempt to reduce some of the human bias involved in the funding approval process by forcing leadership to consider and value impacting factors that they may not have previously. Additionally, an algorithm such as this could be adjusted over time if needed to incorporate other parameters in order to have the desired effects.

A third policy alternative is similar to the current NCI grant awarding policy in support of early career researchers, rather creating a funding initiative that specifically sets aside funds for cancers that disproportionately affect marginalized communities particularly Black and female populations. This would provide at least a minimum amount of funding for these types of cancers' research in an effort to both reduce the funding gap and incentivize researchers to pursue projects in these areas.

The fourth and final policy alternative is the implementation of a system that redistributes funding periodically based on the previous year(s)' cancers with the lowest funding per lethality score. The magnitude of the budget increase would depend on the overall NCI budget, the research budget specifically, and the present amount of funding for that specific type of cancer. This would aim to improve conditions for the most underfunded cancers regardless of the most

affected populations; however, this would also impact Black and female populations as a result of improving overall funding distribution.

Success Indicators

In order to evaluate the success of each of these alternatives, three indicators have been selected. First is the reduction in difference in funding per life years lost (funding per lethality score) between underfunded cancers that disproportionately affect Black and female populations (colorectal, uterine, and cervical) and better funded cancers such as breast and prostate cancer. Second is the overall reduction in the range and standard deviation of funding across all cancer types. Third is the improved outcomes of the cancers of focus- colorectal, uterine, and cervical. This means improvements in explicit and measurable results such as decreased mortality rates and patient reported outcomes such as reduction in pain/symptoms specific to their disease(*Definition of Outcome - NCI Dictionary of Cancer Terms - NCI, 2011*).

	Difference in Funding per Lethality Score	Range and Standard Deviation of Funding	Patient Outcomes of Specified Cancers
No Change	No Change	No Change/Increase	No Change
Funding Algorithm	Decrease	No Change/Decrease	Improved
Black and Female Population Funding Initiative	Decrease	No Change/Decrease	Improved
Periodic Lowest Funding per Lethality Increase	Decrease	Decrease	Improved

Table 2- Success Indicators

Discussion/Results

Projected Outcomes: No Change

The outcome of the first alternative, no change in policy, would be a continuation of current funding and medical trends. This strategy would likely result in the continuance of a

relatively stable gap in funding between breast cancer and colorectal, cervical, and uterine cancers with mild fluctuations as is seen in the funding reports from 2015-2020(2021 *NCI Budget Fact Book - Research Funding - NCI, 2022*). Moreover, the difference in funding per lethality score will also likely remain stable, as there has been little significant change in this metric in recent years, as seen in Figure 1. Similarly, the trend of increasing standard deviation, as seen in Table 1, would also likely continue, indicating the distribution of amount funding per cancer type becoming more widely dispersed. As there are no set regulations for NCI leadership to consider in terms of funding per type of cancer research, it is possible that these gaps could change; however, there is no indication this will be the case. The only foreseen possibility for an improvement in funding to lethality scores is a significant advancement in treatments for any of the aforementioned types of cancer, which would affect the average prognosis of the disease and reduce the number of life years lost. However, a possible new medical discovery cannot be relied on to occur, and change the possible outcomes of this strategy. As such, there is nothing that would suggest any improvements in the disparities affecting Black and female populations.

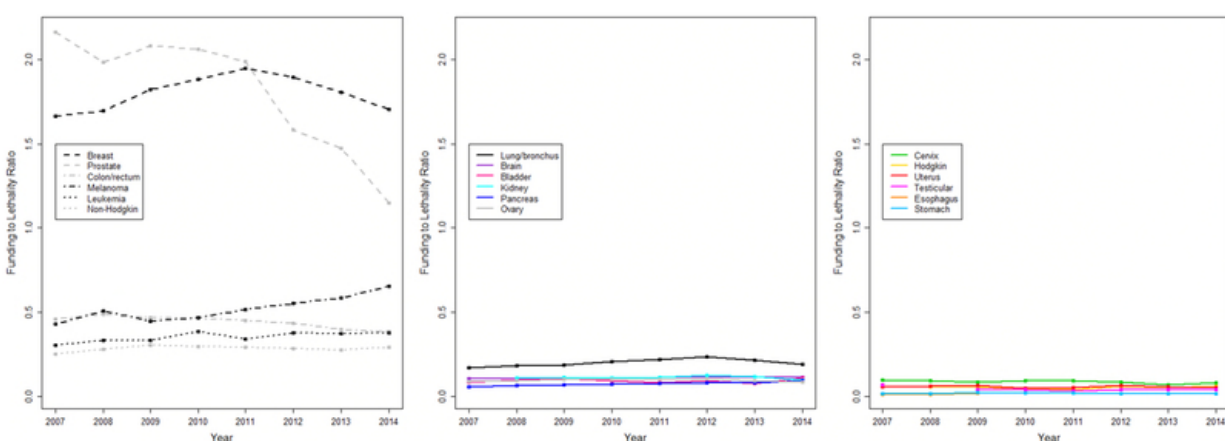


Figure 1- Funding to Lethality Trends 2007-2014(Spencer et al., 2019)

Projected Outcomes: Algorithm for NCI Grant Approval

With an NCI grant approval algorithm that has explicit consideration of factors that more commonly affect a patient's prognosis rather than the overall population-based risk factors,

including lethality and patient demographics, funding for cancers like colorectal, uterine, and cervical, would receive more funding. The projected result of this change would include a reduction in the difference in funding per lethality score between breast and prostate cancers and the specified underfunded cancers. Specifically, acknowledging that patient demographics can impact the resources available to cancer patients will allow for more funding to be allocated towards affected cancer types. Moreover, increases in funding with cancers with worse prognoses would likely improve outcomes, due to the positive correlation between funding and survival rate (*NIH and NCI Funding for Pancreatic Cancer Research – Pancreatic Cancer Action Network*, n.d.). This would additionally contribute to the increase in funding per lethality score, decreasing the difference between scores of the specified better funded and underfunded cancers. Use of this algorithm could also make the funding distribution more even across cancer types, as there would be less funding concentrated just towards cancers with high levels of incidence and lower mortality rates. However, the resulting funding distribution would depend on how much emphasis the algorithm placed on each category it considered. As such, it is possible that the implementation would not necessarily reduce the range between the highest and lowest funded cancers and the standard deviation among funding, rather it would just change which cancers receive irregular levels of funding.

Projected Outcomes: Marginalized Community Funding Initiative

The projected outcomes for the third policy alternative of a funding initiative for marginalized communities are similar to those of the previous alternative. Firstly, the dedicated funding towards cancers affecting Black and female populations would likely improve the funding per lethality score- reducing the disparity between these cancers and breast and prostate cancers. Depending on the effects on allocation of funding to other cancers this initiative could

result in an improved funding distribution or no significant change. Should current grant allocations patterns remain the same apart from the boost in funding for cancers affecting Black and female populations, the range and standard deviation in funding would decrease as a result of the lower funded cancers receiving more funding. However, should grant allocation adjust such that initiative funding was the only source of funding for these cancers- funding distribution would not change significantly. Lastly, apart from the improved outcomes resulting from increased funding, an initiative encouraging and incentivizing research for these cancers would progress research for treatments, improving patient outcomes.

Projected Outcomes: Periodic Funding Increase for Lowest Funding per Lethality

The projected outcomes for the final policy alternative of basing funding allocation based on the previous lowest funding per lethality score would primarily affect the funding distribution. By having a mandated periodic increase in funding for the cancer(s) with the lowest funding per lethality score, over time funding would be more evenly distributed by raising the funding for the lowest funding and most fatal cancers. While this would not focus specifically on the funding disparity based on race and sex, this would likely eventually improve the funding and funding per lethality scores for the affected cancers as they are on the lower ends of these metrics. As such, this would likely reduce the difference in funding per lethality score between breast and prostate cancer and colorectal, uterine, and cervical cancers. Moreover, this would improve the patient outcomes for these cancers as a result of the increased funding.

Confront Tradeoffs

Some of the more explicit tradeoffs are laid out in Table 2 above. Specifically, the lack of predictable deliberate improvements in the funding disparities or patient outcomes for the continuation of current policy. Any of the other three proposed policy alternatives would likely

make improvements in any of the three success factors upon current policy. The major tradeoff in between the remaining three policy alternatives is whether or not there is an explicit focus on altering the current circumstances for Black and female populations with underfunded cancers. Alternatives two and three, the NCI grant approval algorithm and marginalized community funding initiative, both explicitly focus on addressing the racial and sex disparity and as a result may not definitively improve the funding distribution overall. In contrast, alternative four, the periodic funding increase for low funding per lethality scores, is projected to help solve this disparity, although it would be indirectly, and as such may not be considered an adequate way to address it.

Policy Recommendation

The policy alternative which best addresses all of the success indicators is alternative four, the periodic increase in funding for the type of cancer with the lowest funding per lethality score. This alternative would likely have the greatest impact on improving the distribution of funding making sure fatality, incidence, and previous levels of funding are all considered when the NCI allocates grant funding. Although this option does not directly address the disparity of funding based on race and sex, it would likely indirectly adequately improve the funding per lethality score and patient outcomes for colorectal, uterine, and cervical cancers, by increasing the funding for these cancers which do have lower funding per lethality scores.

Viewing Through a Critical Theory Framework

One of the fundamental propositions of critical race theory, which can also be applied to sex, is the permanence of race (and sex)(Hughes-Hassell et al., 2009). Both race and sex, along with racism and sexism are part of everyday life and are embedded into the United States government and the ways people think about the law and privilege(Harris, 1993). This idea can

be clearly seen in this topic, as racism and sexism have both ingrained themselves in the grant funding allocation by NCI. Although there is no explicit mention of race or sex in the guidelines for NCI grant approval, the disparity has still been created by the NCI. Moreover, as there has been no clear effort to eradicate this disparity, this demonstrates the thought of critical theories of race and sex that people often view racism and sexism as natural, rather than an action perpetuated by those with power (McNair, 2008). Critical theory of race and sex can also be used to develop policy to address the effects of racism and sexism in the government, including this issue. Policy considering how race and sex have impacted the funding distribution could be an effective way to ensure a more equitable way to allocate NCI funding. However, this would require the federal government to acknowledge and want to fix the current disparities of race and sex.

Conclusion

With cancer being the second leading cause of death in the United States, it is imperative to appropriately fund cancer research (2022 *Cancer Facts & Figures Cancer | Cancer Death Rate Drops*, n.d.). Initiatives such as Cancer Moonshot have increased the NCI budget as part of the effort to expand progress in cancer research. Although Cancer Moonshot acknowledges disparities in access to screening, diagnostic, and treatment tools, there is no mention of any plans to address the inequities or barriers to access (House, 2022). Apart from issues with access, there are also disparities within the NCI funding; cancers that have higher incidences among Black populations and those affecting female reproductive organs, such as lung, colorectal, uterine, and cervical cancers, are underfunded compared to other types of cancer. Title VI of the Civil Rights Act of 1964 prevents federally funded programs from discriminating based on sex and race (Education and Title VI, 2023). As such underfunding cancers that disproportionately

affect Black and female populations would be a violation of this act, and needs to be remedied immediately and explicitly prevented in the future. There are many ways in which this could be done with policy; however, the policy most likely to be effective is by mandating a periodic increase in funding for the type of cancer with the lowest funding per lethality score. This would likely improve the distribution of funding per cancer type, and increase funding for the aforementioned underfunded cancers thereby improving patient outcomes. Overall, this research has shown that race and sex cannot be ignored when implementing policy in the current legal system, doing so results in the continued perpetuation of racism and sexism.

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