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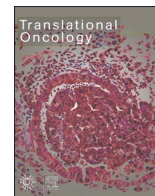
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## NCI's publication affiliation conundrum: Reframing innovation to incentivize an equitable path for advocate representation

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### ABSTRACT

Advocacy engagement has been at the forefront of National Cancer Institute (NCI) efforts to advance scientific discoveries and transform medical interventions. Nonetheless, the journey for advocates has been uneven. Case in Point: NCI publication affiliation rules of engagement pose unique equity challenges while raising questions about structural representation in biomedical research. Abiding by the core rationale that publication affiliation should be tailored to employment status, the NCI has systematically denied research advocate volunteers the opportunity to specifically list NCI as an institutional affiliation on academic publications. Unpacking advocate NCI publication affiliation restrictions and its links with advocacy heritage preservation and convergent science goals poses unique diversity, equity, and inclusion challenges and opportunities. Improving the quality of structural representation in biomedical research requires new theories of action and flexible planning to advance, promote and build capacity for strategic advocacy inclusion and equity within publication affiliation initiatives. Here we highlight several opportunities for how leadership might formulate a radically different vision for NCI's approach. This perspective interrogates the best way forward for ensuring that biomedical employee and volunteer advocate workforce publication affiliation intersections are characterized by increased creativity and representation parity. Imbuing the scientist and clinical researcher archetype with social dimensions, we join NCI critical thinkers in urging employees, funded academics, and volunteer citizen scientists to collectively assume the role as paladins of science and integrity who view the triumphs of making a difference in science alongside the social responsibility of promoting transdisciplinary professionalism and the democratization of science.

### Inclusion-Equity milestones and paradoxes

Guided by the National Institute of Health (NIH) leadership principles for weaving a richer tapestry in the biomedical science workforce [1], the National Cancer Institute (NCI) as the lead federal agency for cancer research supports the integration of advocacy within its collaborative network of programs. The research focus spans from basic cancer cell biology and physical science fundamentals to application – from predictive mathematical modeling, imaging, and nanotechnology – to the optimization of treatment/clinical trial strategies and the

implementation of federal public health policy initiatives.

Drawing on the diverse disciplinary insights, perspectives, and expertise of advocates as knowledge brokers, influencers, bridge-builders, and catalysts for innovation, NCI's specific fifty-year commitment to the value of advocacy team member inclusion within the NCI is laudable. Notably, Mary Lasker, a pioneering advocate had a major role in making the 1971 National Cancer Act a reality by ushering in a new era of patient engagement and advocacy in the development of cancer clinical trials [2,3].

Subsequently, the Specialized Programs of Research Excellence

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(SPORE<sup>a</sup>), Cancer Research Network (SWOG<sup>b</sup>) as part of the NCI National Clinical Trials Network (NCTN<sup>c</sup>), and the NCI Council of Research Advocates (NCRA<sup>d</sup>), the Cancer Systems Biology Consortium (CSBC<sup>e</sup>), the Physical Sciences-Oncology Centers (PS-OCs<sup>f</sup>), and Physical Sciences-Oncology Projects (PS-OPs<sup>g</sup>), revolutionized cancer care by ensuring that patient voices get heard as founding members at program inception.

According to Doug Lowy, NCI Principal Deputy Director, “Research advocates play a vital role in shaping NCI’s work. They challenge us and ensure that we never lose sight of what we are here to do—which is to improve patient outcomes by advancing cancer research. We can’t do this without the unique perspectives research advocates bring” (Lowy) [4].

Yet, while it is fair to say that advocacy engagement has been at the forefront of government and academic efforts to advance scientific discoveries and enhance medical innovation [5–19], concerns regarding compensation, data access, system equipoise, presentation/publication acknowledgement, and decision-making autonomy pose diversity, equity, and inclusion (DE&I) challenges (see Reports from: National Health Council (NHC<sup>h</sup>); Patient Centered Outcomes Research Institute (PCORI<sup>i</sup>); Clinical Research as a Care Option (CRAACO<sup>j</sup>); Drug Information Association (DIA<sup>k</sup>); Biotechnology Innovation Organization (BIO<sup>l</sup>).

As pointed out in these reports, advocates have grappled with a myriad of inconvenient “representativeness” barriers and gaps in building new horizons within science and oncology settings. Despite the plethora of laudable advocate engagements, what is emerging is our burgeoning concern that parity has not been fully extended to governance models. We suggest that progress is coming at a price. How should we meet these challenges?

Representing the diverse voices of basic, translational, clinical, legal, ethics, and convergent science-art-advocacy cancer expertise, we discuss needed culture and process change as pressing priority themes [20]. We specifically explore the best way forward for ensuring that NCI biomedical scientist, clinician, administrative, and volunteer advocate workforce publication affiliation intersections are characterized by increased flexibility, equality, inclusivity, and representation parity.

Although leveraging publication affiliation intersections to advance equitable collaboration with advocates is a controversial restrictive priority focus for some, our commitment to raising the visibility and proactive involvement of NCI funded or affiliated stakeholders in addressing structural inequities and public policy change remains. As palladins of science and integrity, we propose that unpacking the complexities and conundrums of advocate NCI publication affiliation practices, as well as convergent science and transdisciplinary professionalism goals has major implications for “weaving a richer tapestry” in the biomedical science workforce.

Following the lead of iconic behavioral scientists and innovation strategists who examined some of the ironies and limitations in the conduct of AIDS biomedical research processes [21,22], the tensions between expertise and democracy in basic and clinical settings [23,24], as well as alien thinking [25], we argue for the importance of applying a collaborative intersectional science policy lens for reimagining and reframing innovation to break down barriers and democratize research processes [26].

### Unraveling the complexities of NCI publication affiliation practices

NCI publication affiliation rules of engagement pose unique equity challenges while raising questions about structural representation in biomedical research. NCI funded academics do not claim NCI as an affiliation on publications. Instead, authors reference their institution and list NCI grant support in the acknowledgement section of all funded publications. Abiding by the core rationale that publication affiliation should be tailored to employment status, the NCI has systematically

denied research advocate volunteers the opportunity to specifically list NCI as an institutional affiliation on any academic presentations and publications.

Regardless of the recent decision to now reverse course by allowing vetted embedded volunteer research advocates to reference NCI as their affiliation on scholarly and community presentations, structural distinctions remain. Ironically, even when publishing a scholarly article whose content represents NCI’s vested interest and has gone through the scrutiny of a government approval “clearance” process, advocates, like their academic peers, are asked to affiliate with the funded Center with which they associate or alternatively a cancer organization to which they are connected.

Why should this matter?

To begin with, publication affiliation access and context is a critical acknowledgement of the status of the contributor. This is particularly important for independent advocates who do not have other research, academic or institutional affiliations.

Furthermore, publication in a peer-reviewed journal is a highly competitive and esteemed honor. While advocate authors may reference their NCI roles in an Acknowledgement Section, this may not carry the same recognition or status as also listing NCI as the institutional affiliation on the manuscript.

Political affiliation with a particular article in which the authors make specific points that could run counter to government policy could preclude NCI leadership from acknowledging association to the publication. Nevertheless, the practice of barring advocates from listing NCI as an affiliation raises compelling concerns regarding NCI’s goal of ensuring diversity of thought and background to drive science discoveries and provide better treatment for cancer.

An important consideration is that since NCI uses publication affiliation as a tool for tracking the evidence of research output, unless the literature is vigorously mined, advocate authors who list professional organization affiliations remain hidden as NCI contributors.

Finally, while researchers, administrators, and advocates work with inclusivity and respect for one another within a supportive environment, the role distinction between employees and volunteer advocates has become a defining feature. While inequality as a codified construct of advocacy is arguable, it is worth noting that the ubiquitous double standard between employees and nonemployees poses a threat to the democratization of science.

Given these systemic structural challenges, advocates are at a critical inflection point awakening to the uncertainty derived from the legacy of representation tokenism, uncertainty and liminality... a tenuous legacy in which the advocate is “betwixt and between” lacking equal status.

Contemplating transformative approaches for preserving the legacies of advocacy publication affiliation engagement, the community remains hopeful that unraveling the roots of this situation “opens the door to a world of contingency where events and meanings – indeed ‘reality itself’ – can be molded and carried in different directions.” [27]

### Tackling barriers in NCI advocate publication affiliation practices

Making strides to bend, reshape, and ultimately dismantle the drivers of structural bias requires a concerted sense of shared purpose and flexibility. Focusing on understanding the drivers of current leadership decisions, and specifically what works and what does not work, we pose a series of questions:

- 1 What incentive structures are holding barriers in place? Is the rationale for excluding advocates anchored by discretionary, ethical, legal, or regulatory guidance?
- 2 What do NCI team leaders think their respective roles are in defining reciprocal goals, instituting power, and protecting privilege?

- 3 How can the NCI provide representation equality for non-government employees without compromising the integrity of entrenched structural and cultural norms?
- 4 What are the challenges and opportunities for ensuring equity in advocate publication affiliation access? What is the burden to benefit ratio for choices made?
- 5 Are team members aligned or divided on the appropriateness of extending publication affiliation opportunities?
- 6 What if the author is an independent volunteer advocate without a “home” institution other than the NCI as the place where the work took place?

We know that many challenges are still ahead in reframing publication affiliation practices, including:

- Differentiating entrenched practices from legal mandates; stakeholders must ensure that the architects of restrictive publication affiliation rules have access to current thinking on public policy DE&I principles and imperatives.
- Changing the publication paradigm from status quo thinking to innovative adaptive initiatives [28–32] will also require new training strategies for rejecting policy extremes while empowering NCI leadership and affiliated advocates and researchers to collectively consider needed culture and process changes that allow meaningful, sustainable and ethical advocate publication engagements.
- Relinquishing their “passenger” status, niche agnostic advocate “co-pilots” must help steer policymakers towards applying the tangible lessons of AIDS advocacy [33] when confronting the tensions in NCI publication affiliation practices.

Together all stakeholders must collectively recognize, unpack, and address patterns of unconscious bias or personal complacency towards systemic representation disparities. Although all of us have implicit biases, as a community we can take steps to mitigate and dismantle inequitable structural policies.

Ultimately, a revitalized vision for NCI’s approach to advocate publication affiliation will require multipronged shifts at the institutional and investigator levels. Ideally strategies will be grounded in originality as well as solid metrics that reflect team members priorities for sharing power, extending privilege, and ensuring diversity of thought in operationalizing, measuring, spotlighting, and disseminating advocate publications.

Importantly, looking back, with real world data pulled from mining NCI and PubMed records, we must let the record show how advocate authors contributed to driving basic science discoveries towards translation and the transformation of treatment. Bridging this distance for the path forward will require a coordinated effort that involves dedicating resources towards cataloging the fragmented elements of NCI advocacy publication records.

## Discussion

Despite the historic and increasing scope of diverse productive NCI advocate involvements across the research continuum, recognition of the published contributions made by dedicated advocates are often absent, hidden, or underprioritized given the restrictions for listing NCI as an affiliation.

Among the emerging lessons is that we are in the midst of an important, albeit controversial, social justice reckoning that hopefully will set an example for science and society. We speak to the concerns of perpetuating structural polarization and the state of suspense of advocate liminality—to the fact that advocates are empowered as well as vulnerable to the way NCI’s publication affiliation mission, credo, and vision are fundamentally intertwined and at odds with advocate equity

imperatives.

Institutional influences impacting publication policies pose a lingering underappreciated structural barrier to the contribution and professional currency of dedicated, volunteer advocate members, whose indefatigable work to advance NCI’s impactful basic/translational science and facilitate the dissemination of programmatic outreach and education approaches is at risk of oblivion or distortion.

Unless NCI advocate publication affiliation restrictions are lifted, historians of science will face challenges recognizing the contributions of advocate authors as well as the investments of government officials who put enormous trust in the contributions of lay citizen scientists.

The science and practice of advocacy input and credibility continues to evolve rapidly, and it is critical to the future of sustainable NCI funded transdisciplinary team science, making progress for patients, that publication processes continue to pivot and evolve in tandem.

According to Dr. Ned Sharpless, NCI Director, “In cancer, the challenges are too great, the progress too promising, not to embrace and lift up the voice of the best minds and most innovative ideas as we continue our work against cancer. We must confront the fact that our efforts in the past have fallen short of this ideal. We must and will do better” (Sharpless [34]).

As NCI continues to leverage its decades of commitment to advocacy dignity and equity, it must face the uncomfortable fact that publication affiliation practices have fallen short of the diversification of advocate representation as an imperative for NCI’s successful team functioning.

We end with a proactive Call to Action: Pivot for Change

- The time is now to disambiguate, mitigate, and eliminate underlying system level threats of structural bias in publication affiliation practices.
- In order to redefine, amplify, and move fully integrated equitable government wide advocate publication affiliation practices forward, government leadership and every institution supported by NCI funding must seize a disruptive opportunity to transcend disciplinary silos, institutional boundaries, and the complexities of organizational resistance.
- NCI leadership should establish internal and external independent transdisciplinary task forces to find the best ways forward for altering overlooked systemic bias in advocate publication affiliation opportunities.
- Leadership must configure how advocate authors specifically help drive science discovery, catalyze innovative clinical research, and leverage data design in the context of ultimately improving patient outcomes.
- In designing transformative policies for rethinking advocate publication affiliation access, government and academic leadership must take a more nuanced focus on resilient infrastructure, integrated metrics approaches, planning considerations for harmonizing practices and setting rigorous milestones, open honest self-reflective communication, and the implementation of flexible reasonable quality control measures.

Unequivocally, although there are significant hurdles to overcome, we remain inspired by prominent government and academic leaders who promote innovative cultural and structural change to further strengthen equity in biomedical research settings [35–37].

Joining these critical thinkers in imbuing the scientist and clinical researcher archetype with social dimensions, we urge NCI employees, funded academics, and volunteer citizen scientists to collectively assume the role as paladins of science and integrity who view the triumphs of making a difference in science alongside the responsibility of promoting advocate heritage preservation, transdisciplinary professionalism, and transformative change in “weaving a richer tapestry” in biomedical research employee and advocate workforce publication affiliation intersections.

## Webpages

a. <https://www.cancer.gov/about-nci/budget/fact-book/extramural-programs/spores> b. <https://www.swog.org> c. <https://www.cancer.gov/research/infrastructure/clinical-trials/nctn> d. <https://deainfo.nci.nih.gov/advisory/ncra/ncra.htm> e. <https://csbconsortium.org> f. <https://physics.cancer.gov> g. <https://nationalhealthcouncil.org/2020-annual-report/> h. <https://www.pcori.org/2019-annual-report> i. <https://theconferenceforum.org/conferences/clinical-research-as-a-care-option/overview/> j. <https://www.diaglobal.org/en/get-involved/patients> k. <https://archive.bio.org/advocacy>

## CRedit authorship contribution statement

**Susan Samson:** Conceptualization, Writing – original draft, Writing – review & editing. **Jason J. Northey:** Writing – review & editing. **Irene Acerbi:** Writing – review & editing. **Andrei Goga:** Writing – review & editing. **Carl L. Flink:** Writing – review & editing. **Valerie M. Weaver:** Writing – review & editing. **Mark A. LaBarge:** Writing – review & editing.

## Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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