

Just Dissemination of Genomics-Informed Public Health Applications: Time to Deepen Our Public Engagement Approaches

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Introduction

Genomics-informed applications with evidence to support health benefit are not being equitably distributed [1–3]. This is bearing out very clearly in the context of cancer. Evidence-based applications in cancer genomics are informing new cancer therapies, screening, and prevention options. In terms of distribution inequities, African American women with cancer have been consistently and significantly less likely to be referred for and to receive cancer genetic services than white women [1–3].

This is concerning because population-based cancer screening and prevention informed by genomics (e.g., family history assessment for hereditary breast and ovarian cancer [HBOC] syndromes) is now supported by several national organizations [4, 5]. Family history screening to guide the appropriateness of genetic counseling and testing for HBOC syndrome holds particular value for African American women. The hormone receptor-negative breast cancers that are most strongly linked to pathogenic genetic variants are

more common among African American women than other ethnicities – except the Ashkenazi Jewish [6, 7]. African American women generally continue to be diagnosed at later stages and are more likely than white women to die of breast cancer [8]. The avoidable cancer mortalities among African American women represent what some scholars refer to as a “perfect storm,” that is, the confluence of biology/genomics, social adversity exposure, care access/patterns of use, and other systematic health system inequities [9]. As a result, the American College of Radiology now recommends that black women begin discussions about breast cancer risk at age 30 [10]. However, most HBOC screening efforts have been deployed in settings with poor representation of racial-ethnic minorities, a pattern that supports further entrenchment of health disparities [11].

If we are to ensure just access and informed decision-making regarding the uptake of evidence-based genomic applications beyond clinical contexts in diverse populations, it is imperative to enhance our engagement strategies with marginalized communities. To do so, we suggest that we need to go deeper with public engagement and empower marginalized communities to thoughtfully participate in developing strategies that improve service reach and uptake. Arguably deeper public engagement is called for in the case of complex health topics that involve new or controversial advances, where health priority setting requires balancing multiple trade-offs [12]. Input

from members of the public may be especially helpful, when there is a sizable gap in scientific and public knowledge.

The case of family history screening for HBOC and its relevance for those of African ancestry (AAAn) involve many challenges that make it ideal for deeper public engagement. For example, the demographic and cancer-related data used to develop genetic risk assessment models are mostly derived from white populations, and their applicability to populations of AAAn are not well understood. The underrepresentation of populations of AAAn in HBOC basic science, genetic testing, treatment, and prevention research also means that African American women are more likely to receive uncertain genetic test results [13]. This may leave African American women and their family members, who are otherwise healthy, with heightened risk awareness and no clear course of action [14]. A universal feature of population screening is that most of those screened will be found to be at low genetic risk. In the case of HBOC, this is 85–95% of those who complete family history screening [15]. In our prior work, we found that African American women were more likely than white women to misunderstand negative HBOC screening results to mean they were at lower risk for breast cancer, rather than accurately understanding they were at lower risk for carrying a genetic mutation [16]. These misunderstandings might inadvertently discourage African American women from routine mammography for themselves and other family members. African American women in our study also were less likely than white women to accept the legitimacy of their HBOC results [16]. This is consistent with the documented mistrust of health delivery systems as a result of historical experiences and lived experiences of discrimination and harm among African American communities [17].

For the targeted audiences to thoughtfully consider the application of genomics-informed health interventions, they need to be equipped with an understanding of potentially complex trade-offs and be empowered to evaluate these factors in conjunction with the concerns and priorities unique to their communities. In turn, such engagement can improve the probability that health promotion programs and policies will be relevant, successful, and acceptable.

To date, efforts aimed at public engagement to explore inequities in the adoption of genetic services, for instance, have predominantly depended on methodologies such as focus groups and cross-sectional surveys [18, 19]. While surveys and focus group methodologies are widely accepted, feasible, and relatively low in cost,

arguably these approaches do not enable participants to provide well-informed input. Information processing theories suggest these approaches likely do not motivate participants to do the work of intentional reflection, consider the complexities of new information, or feel culturally empowered to believe that their viewpoints can make a difference [20]. This may be especially limiting in guiding interventions and policies in complex health contexts that are unfamiliar to target audiences.

Adopting strategies higher on the public engagement continuum, as delineated by Nunn et al. [12], which align with coproduction and empower the public to continuously and actively contribute to decision-making, necessitate prolonged time commitments and incentives. These aspects inherently elevate costs. Thus, it is not surprising that a review of public engagement within the genomics context showed these more resource-intensive methods to be used infrequently [12].

Methods such as democratic deliberation (DD) have been utilized to facilitate public engagement in deliberation and consensus-building on policy matters [21]. Unlike the techniques used in focus groups, DD presents a unique process wherein individuals initially acquire knowledge of different – and at times conflicting – viewpoints and interests. Participants then deliberate about different solutions and strive to reach consensus on recommendations to optimize the common good. Compared to focus groups, DD processes are designed to equip a diverse group of citizens, aiming to provide an informed public opinion [22]. This is attributed to the opportunity provided to citizens to thoughtfully assess the implications of diverse perspectives on a crucial issue – a consideration that extends beyond personal implications to include the overall well-being of the public (Table 1).

Using a Deliberation Process to Assess the Value of Targeting Communities of AAAn for HBOC Screening

At first glance, extensive public engagement such as deliberative democracy may seem infeasible both in time and needed resources. In 2020, with funding from NCI, we set out to test such a method for feasibility and quality of data output [23]. Briefly, we collaborated with community-based networks to engage citizens of AAAn (i.e., self-identified as black or biracial including black) in southwest Georgia to be part of a “deliberation conference.” Participants reflected diverse backgrounds and experiences in terms of age (mean 48.7, SD = 11.6), gender (19 [79%] females), education (21 out of 24 report

Table 1. Comparison of public engagement strategies in response to key elements of informed participation

Key elements of informed public engagement	Deliberative democracy	Survey	Interview	Focus group	Advisory group	Citizen science
1. Targeted recruitment to include diverse viewpoints	+	–	–	–	+	–
2. Engage in a co-learning process to generate informed perspectives	+	–	–	+	+	+
3. Encourage a societal perspective	+	–	–	–	–	–
4. Allow the community to weigh different options	+	–	–	–	+	+
5. Evaluate the quality of engagement process	+	–	–	–	–	–

some college), and employment status ($n = 5$ unemployed/self-employed, $n = 11$ employed, $n = 7$ retired), with a majority being long-term residents (88%) and having faith involvement (88%).

The DD process involves these key principles: *Consideration of Balanced and Factual Information*: members should obtain a basic and unbiased understanding of the issues and trade-offs, which enables a productive discussion on the matter at hand. The goal is to present scientific information free of distortions or persuasive attempts. *Inclusivity*: the deliberation group should embody diverse citizen and consumer perspectives and experiences. To achieve a truly DD, no segment of society should be marginalized or excluded. *Justification and Reflection*: equal opportunity must be given to all members to participate in the discussion and deliberate. Members are expected to justify their views based on the provided information, and reflecting on others' viewpoints before group consensus is reached. *Common Good Perspective*: participants are encouraged to consider a societal viewpoint on the issue, with deliberations focused on societal benefit rather than individual gains.

Deliberation Enabled a Nuanced Weighing of Pros and Cons

The pros of targeted screening were found to be consistent with the prior studies based on survey and focus group methods [19]. Five thematic areas (Fig. 1) emerged regarding the pros of targeting communities of AAn for HBOC screening: early detection to save life, enable self-management of cancer risks, targeting could equalize access to genetic services, increased awareness of and participation in cancer genetic services among individuals of AAn, and the latter would increase the relevance of scientific findings for this population.

Again, similar to prior less intensive engagement strategies, participants in our deliberation generated a wide-ranging and rich view of the potential cons associated with targeted HBOC screening. Participants generated eight theme areas of cons: risk of insurance discrimination, backlash from other populations who might consider targeting as receiving special attention, the possibility of inconclusive or inaccurate results leading to unnecessary invasive treatment, the cost of follow-up preventive treatments, and the difficulties associated with identifying those of African American descent.

The Pros Appear to Outweigh the Cons

Surveys and focus group interviews likely would stop here in the process by noting that citizens of AAn cited more cons than pros to targeted screening for HBOC screening. On the face of it, these findings might be interpreted to mean that citizens of AAn in this context were not strongly supportive of targeted screening. However, despite citizens' facility in generating a broader range of "cons" associated with targeted screening, their support for targeted those of AAn for HBOC screening remained remarkably high, with 22 participants out of 24 in favor at baseline and 23 participants post-deliberation. The potential for saving lives, increasing access to services, and enhancing the quality of genomic science appeared to outweigh the concerns, making targeted screening a worthwhile endeavor. Participants emphasized that any targeting program would need to address the cons they had identified and suggested these cons were addressable.

Results of the deliberation enabled us to contextualize African Americans' concerns about genomic services rather than taken them at face value. The deliberation

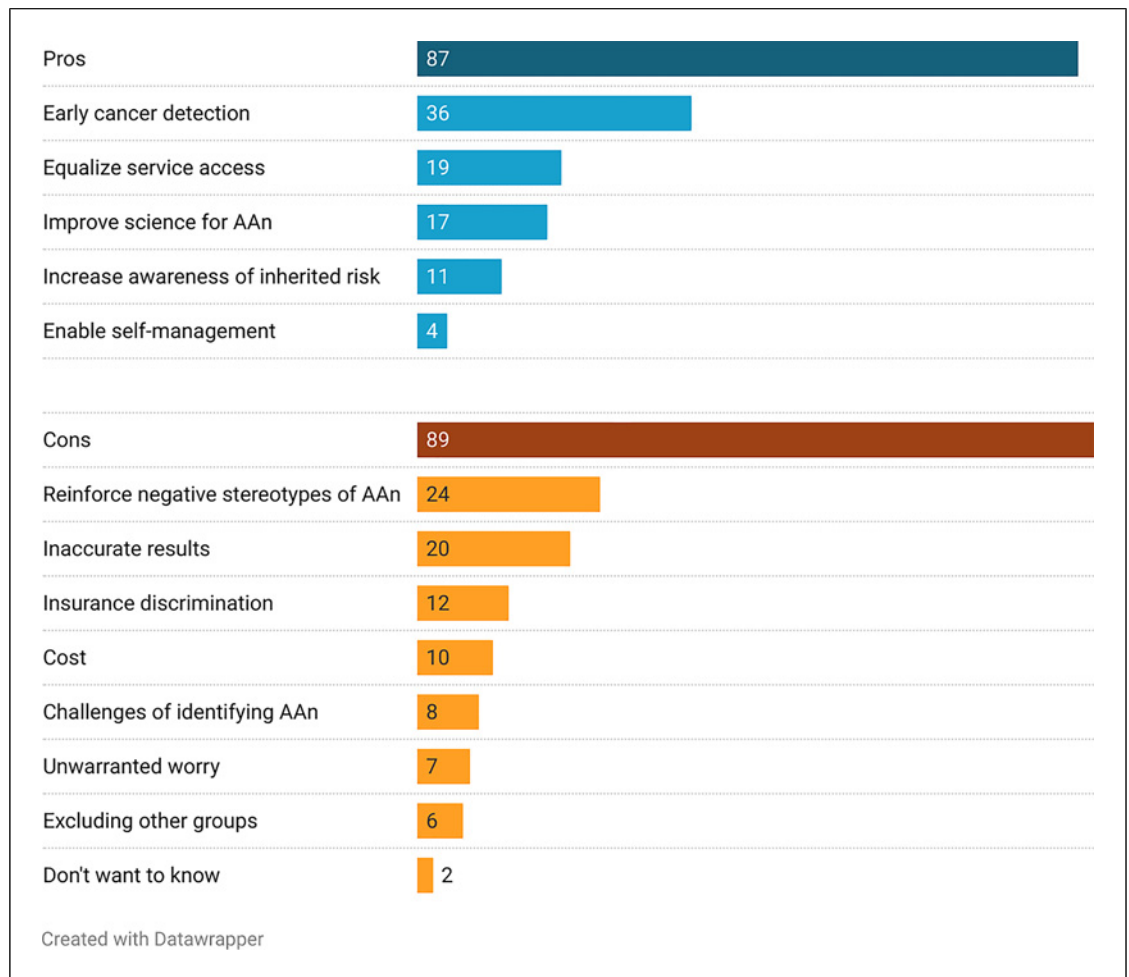


Fig. 1. Counts of pros and cons statements related to targeting individuals of African ancestry (AA) for HBOC screening.

process enabled citizens the opportunity to balance the pros of health and justice with other concerns as a collective. In this way, deeper public engagement enabled a more nuanced understanding of how to appeal to this community regarding uptake of family history screening.

Since this first foray, members of our team have successfully employed deliberation engagement approaches in two other contexts. In collaboration with a faith community, we have conducted an in-person deliberation completely in Spanish with Hispanic/Latino community members to consider accelerating cancer family history screening among their community. With funding from the NCI, we also have conducted a 2-day in-person deliberation conference with community members across Nigeria regarding expansion of HPV screening among HIV+ women living in rural Nigeria.

Key Elements of Informed Public Engagement

Our research team's commitment to amplifying public engagement, specifically via the method of citizen deliberation, has been a cornerstone of our efforts to address cancer health inequities. However, its application may not be universally suitable. Distinctively, citizen deliberation thrives in environments with inherent controversy, a characteristic that is crucial to the deliberative democracy method. These situations often arise when there is a need to choose between varying intervention strategies, contexts with extremely limited resources (e.g. low- and middle-income countries) or when the community's unique insights can contribute to identifying the most effective methods for participant recruitment. Additionally, the community's collective wisdom can be instrumental in addressing potential obstacles to successful

implementation. However, other structured elicitation methods have also been applied such as the Qualitative Story Deck (QSD) [24] that enable creation and weighing of diverse scenarios related to health research and policy in genomics research outreach to African American communities. Like the DD method, QSD involves rapport building, deepening understanding of complex policy questions, and encouraging discussion of unfamiliar and sensitive topics. Regardless of the chosen techniques, we believe that any informed public engagement strategy should embody the following principles:

1. Relies on a proactive and targeted recruitment process to include stakeholders representing diverse viewpoints
2. Builds to a structured process to equip participants with the ability to comprehend all viewpoints pertaining to the issue under consideration
3. Encourages participants to take a societal perspective (i.e., for “the common good”), as the issue in question has impact on the entire community
4. Provides opportunities for collective contemplation, allowing the community to process and weigh options together
5. Conducts regular evaluations of the process, which includes, but is not limited to, an analysis of whether participants are providing informed and justified viewpoints

In closing, strategies such as citizen deliberation enable us to capture the informed and collective wisdom of diverse communities, which is crucial for us to better address the complexities and controversies that often

arise when implementing evidence-based genomics-informed public health applications. In our pursuit of just dissemination of these applications, we must remain committed to not only promoting public engagement but also encouraging inclusive, informed, and high-quality involvement.

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Conflict of Interest Statement

The authors report that there are no competing interests to declare.

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Author Contributions

Yue Guan drafted the perspective. Colleen M. McBride, Sarita Pathak, and Michele C. Gornick reviewed and edited the draft, table, and figure.

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