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A qualitative study of diversity in precision medicine research: The development and stakeholder assessment of a Diversity Decision Map

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Research Article

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Abstract

Introduction: The diversity gap in precision medicine research (PMR) participation has led to efforts to boost the inclusion of underrepresented populations. Yet our prior research shows that study teams need greater support to identify key decision-making issues that influence diversity and equity, weigh competing interests and tradeoffs, and make informed research choices. We therefore developed a Diversity Decision Map (DDM) to support the identification of and dialogue about study practices that impact diversity, inclusion, and equity. *Methods:* The DDM is empirically derived from a qualitative project that included a content analysis of documents, observations of research activities, and interviews with PMR stakeholders. We identified activities that influenced diversity goals and created a visual display of decision-making nodes, their upstream precedents, and downstream consequences. To assess the potential utility of the DDM, we conducted engagements with stakeholder groups (regulatory advisors, researchers, and community advisors). *Results:* These engagements indicated that the DDM helped diverse stakeholder groups trace tradeoffs of different study choices for diversity, inclusion, and equity, and suggest paths forward. Stakeholders agreed that the DDM could facilitate discussion of tradeoffs and decision-making about research resources and practices that impact diversity. Stakeholders felt that different groups could use the DDM to raise questions and dilemmas with each other, and shared suggestions to increase the utility of the DDM. *Conclusion:* Based on a research life course perspective, and real-world research experiences, we developed a tool to make transparent the tradeoffs of research decisions for diversity, inclusion, and equity in PMR.

Introduction

In the US, despite both legislation [1] and federal guidance [2] to diversify participation in clinical trials and clinical research, significant inequities in biomedical research participation persist. In particular, concerns over the diversity gap in genetic studies [3–5] have figured prominently in national discussions about health equity in the context of precision medicine [6–7], a field that "uses information about an individual's genomic, environmental and lifestyle information to . . . provide more a precise approach for the prevention, diagnosis and treatment of disease" [8]. Major figures in the field of precision medicine research (PMR) have underscored the need for equitable inclusion [6–7], arguing that the diversity gap undermines scientific integrity [9–10], raises questions about the potential for inequitable benefit [11], and may reinforce mistrust in the scientific enterprise and research and health care institutions [12–14].

In this article, we introduce an empirically derived [15–20] draft dialogical tool, which we refer to as the Diversity Decision Map (DDM), that is intended to support multi- and cross-stakeholder conversations and more collaborative, deliberate decision-making around how to achieve goals of diversity, inclusion, and equity in PMR. We took inspiration from the burgeoning literature on decision-making in biomedical research and designing research for diversity and equity. That literature includes innovative theoretical frameworks that center community and/or stakeholder participation with a focus on groups with histories of marginalization, under-representation, and harm in biomedical research [e.g., [21–23]. Other frameworks present models and recommend best practices, such as partnering with community stakeholders to develop acceptable approaches to engagement [e.g., [24–26]. The literature also describes approaches for specific research stages, including recruitment, retention, and return of results, as well as specific activities, such as eliciting community input to inform critical decision points in research study design, such as potential research questions and the informed consent process [e.g., [22–23, 27–28].

However, our Ethics of Inclusion Study [15–20] that examined the real-world experiences of PMR funders, investigators, and research team members indicated that stakeholders need something distinct from what the extant literature offers: First, as PMR teams weighed competing interests and constraints, and considered methodological and resource tradeoffs, they needed ways to help anticipate the future consequences of research choices and tradeoffs for diversity, inclusion, and equity [15, 17–18, 20]. Second, PMR teams desired a platform and opportunities to elicit multi-stakeholder dialogue to help shape research decisions along a study's progression [16–19]. In so doing, they hoped that transparency around the rationales for specific study decisions could be enhanced. And third, teams wished for tools to retrospectively reflect on different study choices, and paths taken and not taken, that ended up impacting the inclusivity of their research practices and diversity of participant samples in unanticipated ways [15, 17–18, 20].

Thus, we developed the DDM to support dialogue among stakeholders and advance more informed decision-making about diversity and equity. A primary goal of the DDM is to provide a tool to encourage discussion of tradeoffs that could be and/or are made (e.g., in response to resource constraints, study parameters, funder requirements, etc.) by study investigators, across what we call the research life course. The term "life course" refers to a perspective that understands an individual's health outcomes and trajectory in the context of structural, social, cultural, and other contexts, and that early events, resources, and exposures accumulate to shape future stages of the life course [29]. We apply this perspective to conceptualize research as also having a life course; doing so turns our attention to investigating the contexts, events, and decisions that shape its trajectory.

Below, we describe the process through which the DDM was developed, and how it may be used to catalyze discussions with stakeholders about goals of diversity, inclusion, and equity and how they may be operationalized. We then share the results of engagement sessions we conducted with three groups of stakeholders (regulatory and ethics advisors, researchers, and community advisors) to gauge the DDM's potential utility. Finally, we describe future work needed to optimize the tool to support discussion and dialogue among stakeholders planning and implementing diversity goals in PMR.

Methods & materials

The impetus for the DDM emerged from our Ethics of Inclusion (EOI) Study, a qualitative investigation of conceptions of diversity and their operationalization in five PMR studies across three consortia funded by the NIH [15–20]. Our methods for the EOI Study included a content analysis of 76 documents, including study materials and funding announcements issued by the NIH; approximately 450 hours of observations of study activities, including site and consortium working group calls, and in-person or virtual meetings; and 125 in-depth interviews. Interviews included 102 initial and 23 follow-up interviews, each lasting 60–90 minutes, with funders of PMR research, PMR investigators, research team members, and research participants/participant advisory board members (see Table 1 for EOI interviewee demographic characteristics). Interviewees were purposively recruited based on their involvement in our five study sites or the PMR consortia to which the study sites belonged. All EOI data were analyzed using the principles of constructivist grounded theory [30]. (Additional information about sampling, recruitment, data collection, and analysis methods for the EOI Study can be found in [15–20].)

Table 1. Demographic characteristics of EOI interviewees (N = 102)

	N (Percent)
Gender	
Female	65 (64%)
Male	37 (36%)
Age (years)	
18-65	93 (91%)
65+	9 (9%)
Race	
White	72 (70%)
Black or African American	16 (16%)
American Indian or Alaska Native	0
Asian	6 (6%)
Native Hawaiian or Other Pacific Islander	1 (1%)
Two or more races	3 (3%)
Not reported	4 (4%)
Ethnicity	
Hispanic/Latino	9 (9%)
Not Hispanic/Latino	92 (90%)
Not reported	1 (1%)

To develop early drafts of the DDM, we inductively analyzed our EOI data to identify research activities and decisions that influenced and/or impacted goals of diversity, inclusion, and equity, and created a visual display of these decision-making nodes as part of a research life course. We then further analyzed our data to identify relationships between decisions about specific research activities and the prior "upstream" choices, events, or contexts that shaped those decisions, and their later "downstream" consequences. These analyses produced successive iterations of the DDM, as we continued to add newly identified decision-making nodes and arrows connecting them. The nodes in the DDM and their upstream and downstream connections to other research activities and decisions are not intended to be exhaustive but rather highlight common domains of research identified in our EOI data that were impacted by and influenced by goals of diversity.

Once we had a draft of the DDM, we were interested in receiving input from potential users and to gauge proof of principle: Did the DDM help to convey the importance of decision-making across the research life course? Did exemplar decisions and their upstream determinants and downstream consequences for diversity generate discussion and forward thinking about how to shape PMR studies for achieving goals of inclusion? To assess the potential utility of the DDM, we conducted three engagement sessions, each with a different stakeholder group. These included the regulatory and ethics resource of a clinical and translational science center at an academic medical center (referred to hereafter as "regulatory and ethics advisors"), precision medicine investigators who are part of a genetic research consortium ("researchers"), and a group of community partners with experience advising a clinical translational science institute ("community advisors"). We recruited these groups as follows: The regulatory and ethics advisors were part of an existing working group of a university's

NIH-funded Clinical and Translational Science Award (CTSA) program, and the researchers were part of an existing working group of a genetic research consortium. Both groups met regularly, and we obtained permission to join one of their meetings to conduct our engagements. We recruited the community advisors through a university's CTSA community engagement core, which offers consultations with community advisors: upon our request, the CTSA staff issued an invitation to their pool of community advisors. Because of the relative dearth of EOI data from participants in precision medicine research studies, it was particularly important for us to seek input from community advisors. Our engagements involved 8 regulatory and ethics advisors, 11 precision medicine researchers, and 7 community advisors, for a total of 26 individuals across the three sessions. Only 4 individuals from the researcher group were also interviewees in our EOI Study; all other researchers, and all of the regulatory and ethics advisors and community advisors did not participate in EOI interviews.

During these stakeholder engagements, we began with a presentation of the DDM, explaining the concepts of a research life course, the path dependence of research decisions, and tradeoffs incurred when selecting different decision paths. We offered data-based examples of research decisions, and using the DDM, traced their tradeoffs, upstream determinants, and downstream consequences. We then elicited stakeholders' reactions to the following discussion prompts: What questions and issues about study decisions did the DDM generate? Could they use it to follow operational and methodological choices, surface tradeoffs, and map their consequences through the research life course? Did the issues that surfaced resonate with their own experiences in PMR? Could they see the DDM helping to identify tradeoffs of research paths taken and not taken? Could they see the DDM being useful to them in their future work; if so, how, and what more work on the DDM would be needed? Team members observed and either audio-recorded or took extensive, near-verbatim notes on the stakeholder discussions. After the sessions were complete, the EOI Study team reviewed the recordings and notes and transcribed selected portions of the recorded sessions. We then itemized stakeholders' comments and feedback, collated them by themes, and organized these into tables where we could examine commonalities and differences across stakeholder groups.

Results: The diversity decision map

In Figure 1, we show our current draft of the DDM. In constructing the DDM, it was important to us that it represent our understanding from our EOI data that PMR studies did not proceed linearly from beginning to end, neatly step by step, according to design or plan. Instead, many studies we investigated were built upon previous research efforts or already recruited samples or participants or were conducted in waves with multiple funding sources. Additionally, multiple phases of a PMR study often happened simultaneously as researchers made decisions, tried them out, encountered problems or changing conditions on the ground, and so pivoted and iterated. We also found that the cumulative effect of multiple decisions, that researchers perceived at the time to be relatively mundane, frequently had downstream impacts on the ability of a PMR study to reach diversity goals and implement inclusionary practices. That is, multiple small, ad hoc decisions made upstream shaped and constrained consequential outcomes, including participant diversity, the kinds of data collected, relations with participants or community advisors, and the potential to aggregate data with those of other studies. Research decisions also had a path-dependent and looping nature to them: choices made at one time about one study activity often looped back to shape other activities and options available in the future; similarly, decisions in a PMR study were shaped and constrained by the ecosystems and contexts in which the study was embedded.

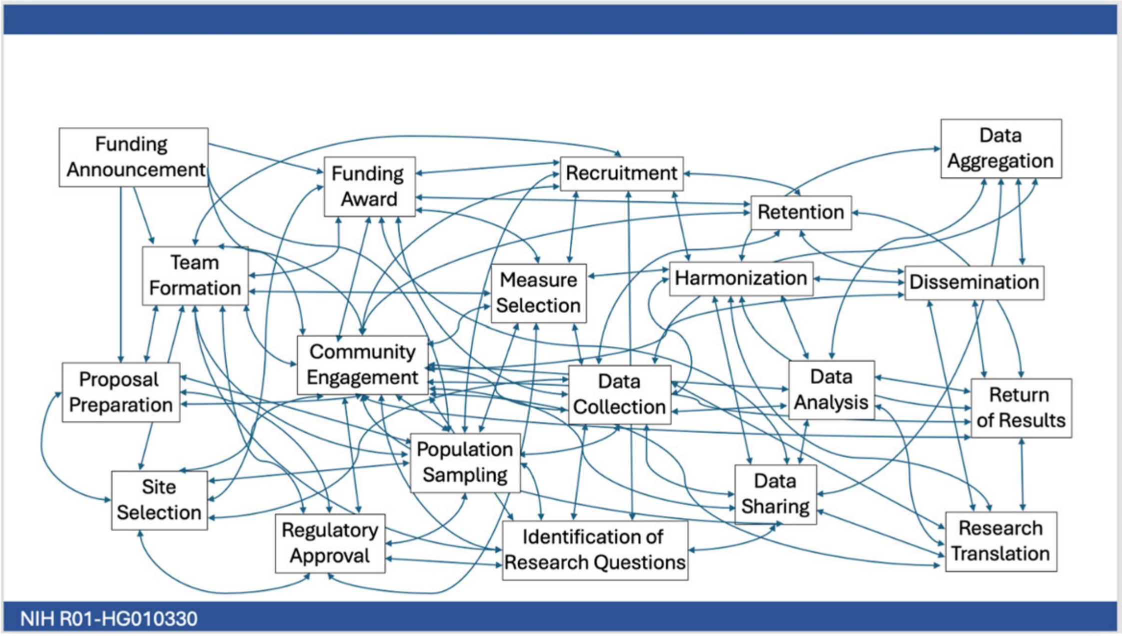

Figure 1. Diversity decisions across the research life course.
Note: arrows linking boxes and research stages are double-headed, to indicate mutual influence and dependence between study activities (i.e., earlier choices about study design and procedures shape subsequent options, and decisions at one stage may require amending previous methods and procedures). Not all possible arrows are depicted.

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Thus, we constructed the DDM to show various research activities across the research life course in boxes, and through the arrows linking boxes to each other, indicate how these activities are connected to and influence one another.

At first glance, the DDM can appear to show a typical progression of research stages, for example, by depicting steps such as *Proposal Preparation* on the left side and *Dissemination* on the right side. However, our EOI data showed that studies did not simply start on the left and move to the right. Therefore, we included the many double-headed arrows linking boxes and research stages to indicate the complex mutual influence among them, both in the path-dependent sense where earlier choices about study design and procedures can shape subsequent options, but also in the iterative sense where decisions at one stage may require backtracking and amending previous methods and procedures. Not all possible arrows are depicted; the specifics of actual studies will inevitably shape whether and how boxes are connected, as well as the directionality of influence and impact.

The DDM is intentionally complex, to reflect the on-the-ground realities of research decision-making as it unfolds in relation to multiple competing demands and resource constraints. Also intentionally, the DDM is not meant as a prescriptive, normative guide for what specific research decisions can and should be made to optimize equity. Instead, we developed the DDM to serve as a useful heuristic and tool to enable stakeholders to identify tradeoffs and facilitate stakeholder dialogue about those tradeoffs, at multiple stages of a study and even when the research is well underway. To do so, we found that the DDM needed to allow stakeholders to locate where they are in the research process (much like a map reader who must pinpoint where they are before navigating their way). Stakeholders would then need to weigh competing interests, consider methodological and resource tradeoffs, anticipate the future consequences of different choices for inclusion and equity, and seek to make informed decisions. The DDM helps to guide the systematic consideration of the potential effects of study decisions about one set of research activities on others, by attending to how boxes are and might be connected to and influence others. Rather than focusing on recommending specific study decisions, best practices, or pathways in the abstract, our DDM seeks to support dialogue, transparency, and decision-making among research stakeholders who face complex on-the-ground constraints, conditions, and contingencies.

To further illustrate how the DDM might be used, we provide two examples based on significant findings from our Ethics of Inclusion Study (additional explication and demonstration of the DDM are also provided in an animated, narrated, and accessible slide show presentation [31]). In the first example (elaborated in our publications [16–17]) represented in Figure 2, the box labeled *Population Sampling* in the bottom middle of the map refers to decisions made about which populations the PMR study would focus on and how those groups are defined. Such choices can be shaped upstream in the research life course, for instance, by guidance from *Funding Announcements* (upper left on DDM) that may stipulate or even require that certain populations be included.

Additionally, population sampling can influence *Team Formation* (see Figure 3, on the left), that is, study team members whose characteristics reflect the populations targeted for participant recruitment might be hired and their involvement will then shape study activities such as *Recruitment* (top middle) strategies to enroll populations prioritized for inclusion [16]. This, in turn, could also influence *Site Selection* (bottom left) where a study may decide to partner with specific clinics with reach and connections to the desired communities and groups targeted for enrollment [17]. This example illustrates how the DDM can be used in studies already in progress: in this case, even though a decision about which populations would be enrolled has been made, the study team could start in the middle of the DDM to anticipate how that decision might shape downstream choices about team hiring and composition, and recruitment sites, in ways that impact diversity and inclusion.

As another example (elaborated in our publication [18]) represented in Figure 4, we focus on the box labeled as

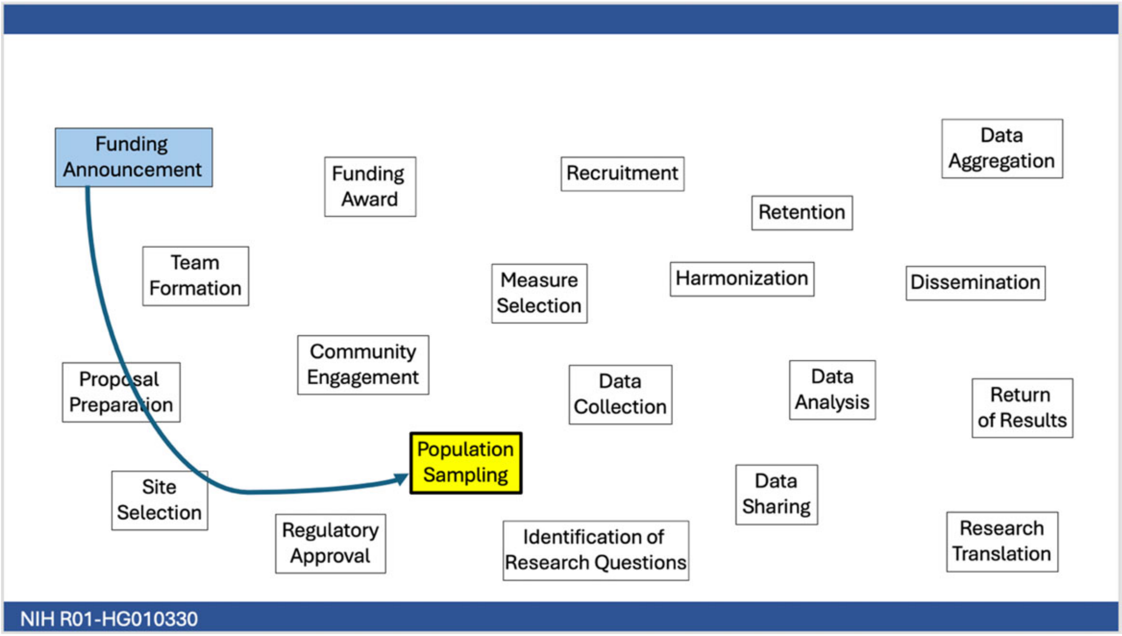

Figure 2. Diversity Decision Map: population sampling example.

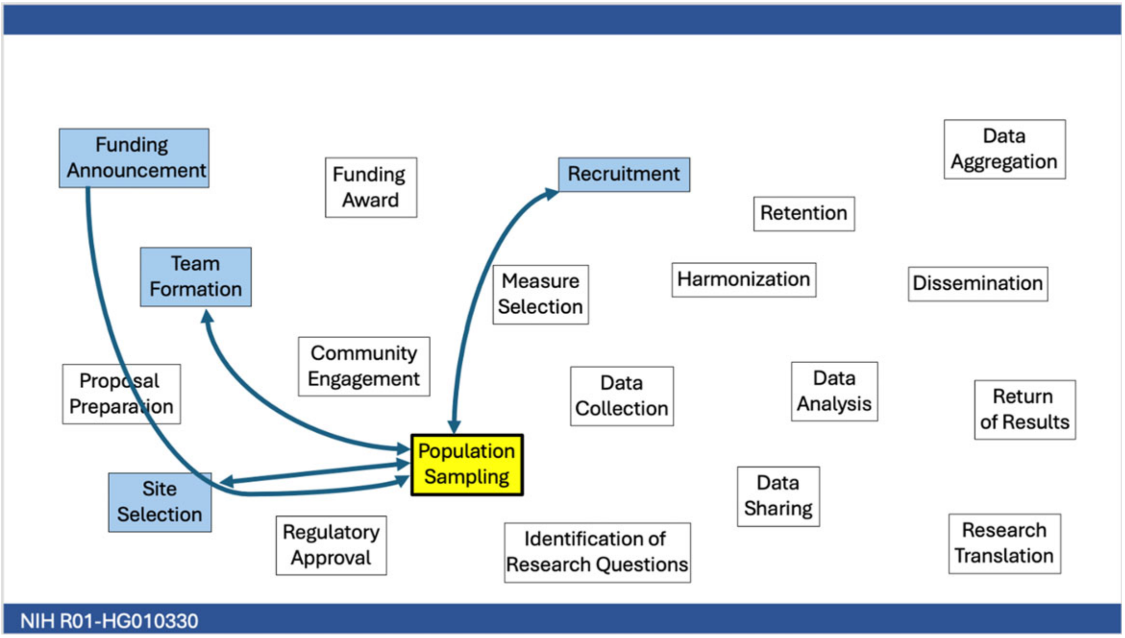

Figure 3. Diversity Decision Map: population sampling example (continued).

Community Engagement found in the center left of the DDM. A series of decisions informs whether, when, and how community engagement is incorporated into the governance of the study throughout the research life course. That is, to what extent do community members participate in decision-making in study activities that are often understood to be shaped by community input, as seen by arrows connected to *Recruitment* and *Retention* (both in top middle), for example, and *Population Sampling* (bottom middle)? But we also link community engagement to other research stages such as *Identification of Research Questions* (bottom center), *Measure Selection* (near center), and *Team Formation* (middle left)—these may be less commonly recognized as connected to community engagement activities. Empirically, we found that decisions about whom to engage, when, and how shaped whether community advisors provided input on what sorts of research questions were pursued, which data were collected and how, and whether leadership and decision-making authority were given to community partners [18]. This reinforces that community engagement can happen at any stage of a study, and when and how it is conducted has implications for a multitude of research activities.

Finally, as seen in Figure 5, community engagement also had spillover effects on *Data Analysis*, *Data Sharing* (both middle right), and *Research Translation* (bottom right), where we found that some community-research partnerships shaped research questions and data collection to be highly local and specific in ways that limited the ability for study data to be aggregated with other data. And the degree of commitment to community engagement affected choices about *Team Formation*: strong commitments to an engaged approach led to community partners needing to be part of study leadership, whereas understandings of community input as advisory meant that community engagement could happen more separately [18].

The stakeholder engagement sessions provided important feedback through which to assess the utility of the DDM (see Table 2). Across the different stakeholder groups, all agreed that a dynamic and user-responsive tool like the DDM was necessary, to facilitate intentional research decision-making that was collaborative and that would optimize the ability of studies to achieve their goals for diversity, inclusion, and equity. They saw the value of the DDM in tracing consequences of study decisions for diversity and inclusion, suggesting paths forward, and showing how important upstream factors and constraints shape research. They also felt the DDM provided a common orienting object that different stakeholders could use to raise important considerations (e.g., budget, team formation, community involvement, etc.) related to diversity and inclusion, and share ideas, questions, and dilemmas with each other. Regulatory and ethics advisors found the DDM useful for simplifying complex concepts as well as raising the challenges of determining meaningful community participation. Precision medicine researchers appreciated the potential for discussing the rationale for research pathways taken and not taken and the potential downstream impacts. Community advisors suggested the importance of dialogue about study-specific contexts and avoiding a researcher-centered understanding of tradeoffs. These sessions indicated that the DDM would catalyze the kinds of discussions and raise the kinds of questions about the consequences of potential research decisions on diversity and inclusion that we hoped it would. These conversations and debates served to support the proof of principle for the DDM.

We also sought feedback from stakeholders on what about the DDM worked, what questions they had, and what could be improved. There were widely ranging opinions about whether the DDM was too prescriptive or too open-ended: some felt it represented particular pathways as being the "ideal" and others as "lesser options"; others thought it needed to indicate a recommended starting point (e.g., beginning with community engagement). Still others emphasized the need for the DDM to offer 'middle road' approaches, present benefits and challenges of different paths taken in balanced ways, and promote a stance of being curious, rather than presenting problems that have to be

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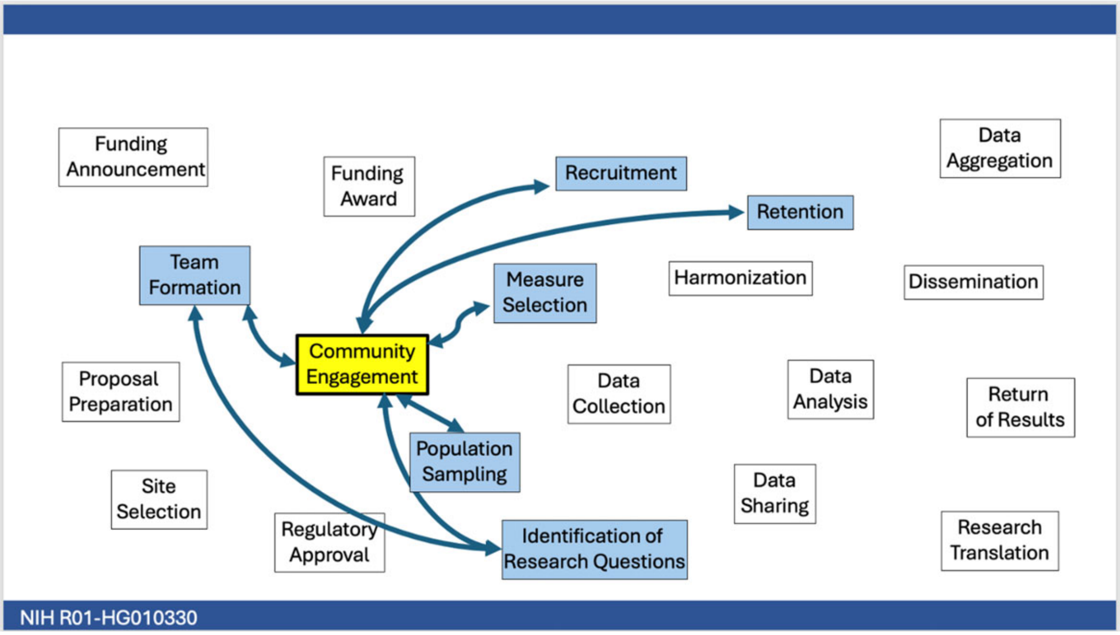

Figure 4. Diversity Decision Map: community engagement example.

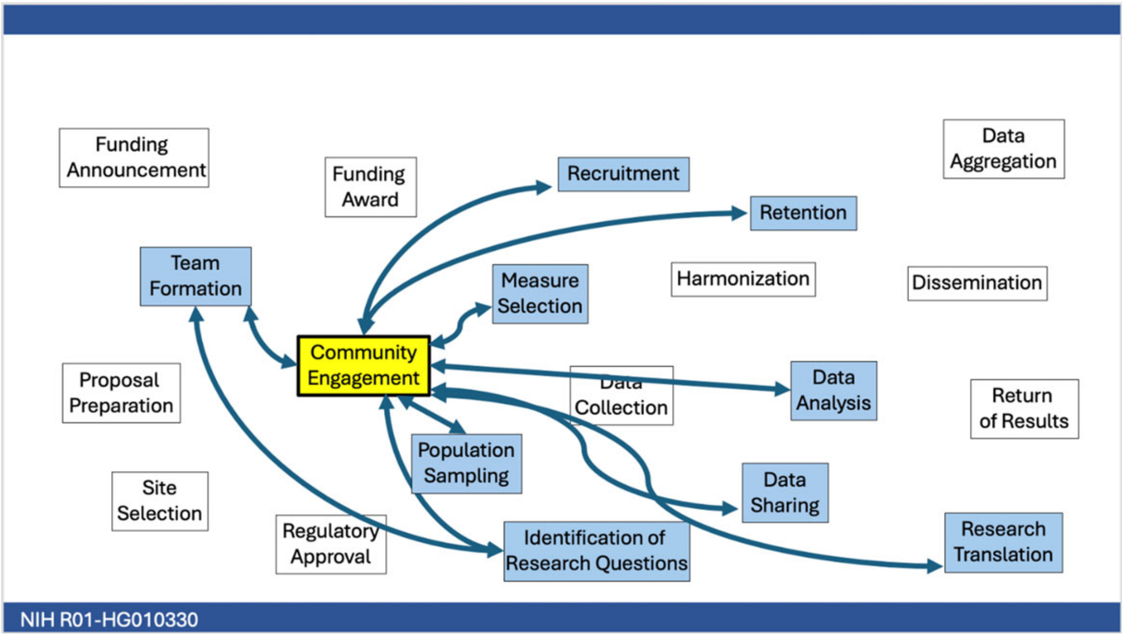

Figure 5. Diversity Decision Map: community engagement example (continued).

addressed; these latter comments align well with our intended purpose. Some stakeholders felt the DDM disproportionately centered researcher perspectives, and that its language and visuals were not appropriate for engaging community representatives. They offered a wide range of other comments for clarification and improvement, including indicating where “hard stops” or “veto power” might be integrated to prevent studies deemed to be problematic from moving forward, making the DDM more interactive, and providing accompanying user resources. Finally, stakeholders also pointed out contextual issues that would constrain the utility of the DDM, such as funder authority to reject certain pathways or community members not having sufficient decision-making authority.

Collectively, the stakeholder feedback led to revisions to the DDM, and were incorporated into our User Guide, along with an accompanying video [31], that we hope can facilitate cross-stakeholder discussions of research decisions and tradeoffs that may affect diversity- and equity-related outcomes. These materials

Table 2. Feedback from stakeholder engagement sessions

Stakeholder Group	Feedback
***Discussion Prompt:* Did our examples help you to understand the tradeoffs by taking one approach over another? Could you use the map to help identify how different study decisions along the research life course influence and are impacted by other decisions at other times?**	
Regulatory & Ethics Advisors	Simplifies complicated concepts, suggests paths forward. Studies "are not democracies"; what is the appropriate level to set the bar for "community-based participation," where community members can make meaningful contributions (not too high or low).
Precision Medicine Researchers	Demonstrates the importance of community voice in shaping research. Paths are too mutually exclusive, examples do not provide a "middle road" approach; one pathway presented as "ideal" but challenging may lead researchers to "shut down because they know they can't go there."
Community Advisors	Value of the map in identifying what happened when you trace a decision and its consequences across the map, "going up, going down, follow it through the map." "The value here is, "have I thought of it?""; can have impacts several steps along the decision path. The map shows the topic (the "what") but not how to proceed (the "how"). A tool to think with, a reminder of what to consider, an approach to intentional decision-making, "taking every opportunity to think about that path, [because] in reality, the constraints are real." The researcher orientation is exclusionary, "raises anxiety," difficult to "parse it out," each line and box.
***Discussion Prompt:* Could you use the map to understand how study decisions have consequences for diversity and inclusion?**	
Regulatory & Ethics Advisors	Having community members in the room may only be a "quick fix, but it may not make a difference" if they feel "uncomfortable with making scientific decisions, or [are] in the minority … [or] have limited decision-making power.
Precision Medicine Researchers	Portray paths that have *not* been taken or that might not benefit from community engagement.
Community Advisors	Map makes clear that "best practices" are not the only practices; there are other paths. Need to consider different types of benefit, whose, at what level (e.g., individual, population, community, environment).
***Discussion Prompt:* What additional information would be helpful? How could the map be improved?**	
Regulatory & Ethics Advisors	Not prescriptive enough. When NIH/funder has decision-making authority and the PI has committed to following through on proposed/funded project, how to account for funder's ability to accept/reject some aspect of project. Clarify how approaches are based on empirical data. Clarify that the DDM may be used for both hypothetical cases/design of future studies as well as in-progress studies.
Precision Medicine Researchers	How to present benefits and challenges of different paths taken in balanced way, so as not to portray some decisions as lesser options.
Community Advisors	Reorient the starting point to ask questions about research design or benefit to the community; "decisions [about these issues] should be happening prior to funding." Missing box for Budget: who decides and how. *Team Formation* doesn't explicitly include community members For *Regulatory Approval*, "should include a requirement for the ethical engagement of community, especially with attention to the potential for "extractive" research and the impact that can have on communities that have historically been harmed" by research. *Community Engagement* is not centered enough throughout. *Community Engagement* should include acknowledgement and repair of historical harms in research that have pushed people away from care, not only related to the current study. The map may not accommodate different types of data and biospecimens, their regulation, and that problematic history. Too researcher-oriented, not appropriate for engaging community participants, including language and visuals. How to indicate where/when there are "hard stops, where participants have veto power," similar to clinical research adverse events; "it can be difficult for the community to interrupt the [research] process once it's in motion." Make map more responsive, not just static. Map must be applicable to the user. Even though the map is very busy, "still want … more info … resources, specific prompts to think through." Incorporate concept of "justice" and/or "human rights" How can the map mirror the process of being curious, rather than presenting problems that have to be wrestled with?

provide the basis for key next steps to increase the DDM's utility, including: incorporating additional research life course stages, making it more interactive, improving it visually, embedding more information as well as concrete examples and cases, and clarifying whether the DDM aims to enhance diversity and inclusion towards broader ends, whether that be statistical representation and/or equitable science.

Discussion

In PMR, there is a need to confront, understand, and trace how diversity and equity are weighed when competing values and constraints of time and resources arise; our DDM aims to help address this need. We also believe the DDM can be used for retroactive reflection on research decisions, or midstream pivoting

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for ongoing studies. As such, this paper offers a different though complementary contribution to the existing literature on biomedical, clinical, and genetic research decision-making and design for diversity and equity, that proposes theoretical frameworks [e.g., [21–23], recommends best practices [e.g., [24–25], describes models or examples [e.g., [26], and/or pertains to specific research activities or parts of the research life course [e.g., [22–23, 27–28]. In contrast, our DDM seeks to take the real-world and on-the-ground experiences of PMR funders, investigators, and research team members as they weighed competing interests and made methodological and resource decisions [15–20], and support dialogue and transparency in designing and conducting PMR to advance inclusion and equity. By identifying when and why expected *and* unexpected tradeoffs occur throughout the research life course, the DDM can help surface and anticipate path dependencies, so that stakeholders can discuss, deliberate, and then guide decisions to produce intended results, rather than unintended consequences.

We also found that the DDM can help identify the structural and institutional-level reforms needed to better facilitate decision-making that advances diversity and inclusion. Path dependencies spanned *across* research studies, in that research institutions became used to their own routines and standard operating procedures, and so the outcomes and experiences of one study for participants and communities affected the conduct and uptake of the next study. Additionally, the DDM directs our attention to how study decisions are shaped and constrained by the policies and practices of the wider PMR ecosystem that includes, for example, funding agencies, regulatory bodies, other research institutions, PMR consortia, professional societies, and scientific norms [32]. As others have observed [33–35], the DDM shows how diversity, inclusion, and equity cannot simply be 'tacked on' to ongoing research. We therefore hope that the DDM (along with our User Guide [31]) may generate new approaches and conversations to address specific challenges to increasing diversity and meeting goals of inclusion.

Use of the DDM in and of itself may well lead to delays in study progress as convening multi-stakeholder conversations about research decisions, pathways, and consequences takes significant time; delays can extend as researchers seek to address complex tradeoffs that have been revealed. However, time to elicit cross-stakeholder perspectives may be well spent if it leads to discussions of how to achieve goals and avoid barriers and pitfalls related to diversity and equity. The feedback we received from several different stakeholder groups demonstrates the proof of concept of the DDM as an organizing heuristic for conversations and debates about how to study decisions at a multitude of research life course stages accumulate to impact diversity, inclusion, and equity in PMR practices, data, and findings. Moreover, because the DDM is an open-ended tool to help stakeholders assess the consequences of research-related decisions for a specific study in specific organizational contexts, its use can lead to a collective understanding of the relative importance of different decisions for diversity and equity. At the same time, the stakeholder engagement sessions identified important critiques and areas for clarification and improvements to the DDM.

Our next steps are to work with clinical and translational science programs and centers that are interested in further developing the DDM into a more interactive and customized tool to support research decision-making that advances diversity, inclusion, and equity. Importantly for us, this future refinement of the DDM and the development of additional accompanying resources (e.g., use cases or exemplar vignettes, discussion prompts) should advance its useability for multiple groups of PMR stakeholders, and its capacity to foster and structure cross-stakeholder discussions and joint deliberations. In its final version, the DDM should be structured yet adaptable for different kinds of PMR studies and research contexts, and in formats that can be used by various stakeholders.

Limitations

Although the DDM is based on substantial empirical data from the EOI Study, the interviews we conducted were primarily with PMR investigators and research staff and observations of PMR activities, and thus reflect the perspectives and demographics (see Table 1) of those groups. Thus, the utility of the DDM for other stakeholder groups, and its generalizability to a wider range of precision medicine research study types and organizational contexts, are not yet fully tested. Because the DDM itself is still a work in progress, more conclusive findings of its efficacy in PMR decision-making will require finalization of the DDM and systematic evaluation of its implementation and impact. This could potentially include qualitative and quantitative survey data about the frequency and nature of DDM use, how diverse stakeholders perceive the DDM, and the effects of using the DDM on PMR life course stages such as the composition of study teams, study decision-making structures and processes, study design and conduct, community engagement, diversity and inclusion metrics as appropriate, and so on. Enabling study teams using the DDM to conduct ongoing assessment themselves could also provide important information on the impact of their research decisions on diversity and inclusion outcomes, and help them to refine their approach. Conducting such assessments will also inform future modifications to the DDM to ensure its utility across PMR study types and research contexts.

Conclusion

We argue that a tool like the Diversity Decision Map can support the design, implementation, and translation of PMR in ways that advance diversity, inclusion, and equity by facilitating awareness of the situational exigencies that PMR stakeholders face and how different choices can lead to different outcomes far downstream. The map enables *temporal* awareness and forward-backward thinking, to mitigate against choices made in direct reaction to the constraints of the moment, by explicitly factoring in mid- to longer-term consequences. The DDM also encourages systems-level thinking, and understanding of PMR as embedded within an ecosystem and set of structural, social, technical, and cultural contexts that shape what it is and what it can be. We hope that using a tool like the DDM will result in clearer understandings of what structurally must change – and how – in the policies, infrastructures, and contexts within which research is conducted, for different decisions to be made and paths to be taken, to center and advance diversity, inclusion, and equity.

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