

Culturally responsive health research: A collaborative design model for equitable and sustainable community impact

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To Cite: Tufte JE, Dungan RE, Attipoe-Dorcoo S. Culturally responsive health research: A collaborative design model for equitable and sustainable community impact. *JHD*. 2021;6(3):429–434.
<https://doi.org/10.21853/JHD.2021.143>

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SUMMARY

Engaging and sustaining equitable collaboration between researchers and other stakeholders can prove challenging. However, health research processes and products often benefit from the collective insights gleaned when diverse partners work together. As such, co-designed and culturally responsive research often yields significant real-world impacts. We explore the need for change and propose a framework for reimagining research as an inherently collective and collaborative effort. Referencing an illustrative case study and using human-centred design approaches to support culturally responsive work, we offer reflections on how to embrace empathetic, inclusive methods that meaningfully engage diverse and under-resourced communities in research co-design.

Key Words

Human-centred design; Trust; Culturally responsive; Patient-centred; Community collaboration

INTRODUCTION

Health services research (HSR) is the science and study of health care and care delivery systems—to determine what works, for whom, at what cost, and under what circumstances. It is an applied field that aims to investigate how health systems work, how to support patients and providers in choosing appropriate care options, and how to generate the insights needed to inform evidence-based health policymaking. The field of HSR produces insights that can inform health systems and services improvement, in order to enhance individual and community health outcomes. This is achieved by generating evidence for and by individuals such as health practitioners and policy makers, as well as members of the general public. However well-intentioned, researchers can end up generating insights irrelevant for informing evidence-based policy and practice because they do not respond to needs in real-world settings. Unfortunately, given problems inherent in traditional research standards and structures, research efforts are sometimes rendered moot or, worse, they bear unintended negative consequences. Research that fails to account for people's lived and living experiences also often fails to produce solutions with sustainable, positive impacts for the involved communities.¹

To counter such occurrences, collective impact and engagement science scholars increasingly celebrate research done “with” and “by” communities, instead of “to” or “for” them. Addressing “wicked” problems—that is, those deemed difficult to solve given their significant social or economic burden and their intersection with other problems²—often require similarly emergent, adaptive, and responsive solutions. By taking an inclusive approach that celebrates the diverse

talents and perspectives each partner brings to a collaboration, we can better co-design research with equitable and sustainable impact.

Increasingly, the HSR field is embracing community and patient stakeholder engagement in health research co-design. In part, this is due to growing recognition that context- and culture-specific research findings prove most likely to contribute directly to improved health outcomes.³ However, attitudinal and implementation challenges still impede partnered research. We propose a framework that can guide researchers in learning how to meaningfully engage partners in culturally responsive health research, and provide an example of a co-designed project demonstrating one application of this framework.

Culturally Responsive Research Framework: Representativeness, Engagement, Sense-making, Personalisation, Empathy, Collaboration, and Trust (RESPECT)

Creating opportunities for co-design that are truly collaborative, rather than tokenistic, can prove challenging without some kind of a guiding framework. The proposed RESPECT Framework outlines the key principles of culturally responsive research design (Table 1).^{4–13}

Table 1: Principles of Culturally Responsive Research Design: RESPECT Framework

Principle	Definition
Representativeness	<ul style="list-style-type: none"> Research findings can only be accurately generalised to a broad population, if the study sample comprises population subgroups in proportions relative to those of the broader population. In research contexts, representativeness can be defined as the extent to which characteristics such as participants, context, and settings can be attributable to those outside the constraints of the study.⁴ Similarly, culturally responsive research co-design often requires input from those closest to the issue or research question at hand.
Engagement	<ul style="list-style-type: none"> To design and conduct culturally responsive research, communities central to (or impacted by) the research must be an integral part of the research process. It is especially critical to incorporate the voices and expertise of historically excluded community members, so their collective insights can aid in advancing health research innovation and producing findings that equitably improve health outcomes.⁵ True engagement extends beyond <i>informing</i> partners about research plans or decisions, and <i>involving</i> them in predetermined or predesigned activities. According to the Patient-Centered Outcomes Research Institute (PCORI), <i>engaging</i> partners requires meaningfully integrating “... patients, caregivers, clinicians, and other healthcare stakeholders throughout the entire research process—from planning the study, to conducting the study, and disseminating study results.”⁶
Sense-making	<ul style="list-style-type: none"> One benefit of engaging diverse voices in the research design process is the resultant access to rich and robust insights that can inform evidence generation. The ability to make meaning from these varied insights is critical for generating findings that are relevant to and applicable in contexts central to research questions. Finding ways to amplify and integrate the experiences of engaged participants is a necessary component of meaning-making.⁷ Resources such as the Cynefin framework⁸ can guide researchers in navigating the chaos and complexities that may emerge from multistakeholder conversations. Using such a framework, researchers can

	<p>maintain the purpose of the project (ie, answering research questions) while making meaning out of the process (ie, helping partners contextualise their experiences).</p>
Personalisation	<ul style="list-style-type: none"> • Cultural responsiveness requires learning and adapting to the particular goals, needs, preferences, and values (GNPV) of project partners. • Centring persons (be it research partners or participants) in the work may involve adapting research design, methodology, or approaches, as well as the modes of research engagement. • All modes of engagement or involvement should honour the culture, interests, interpretations, and power dynamics shaping the contexts or communities central to the research.⁹ • All collaborators should also derive value, returned in forms aligned with their personal or community GNPV, from the partnership.
Empathy	<ul style="list-style-type: none"> • Gass¹⁰ posits that social transformation requires that all people work with both their hearts and minds. By engaging in work that exercises empathy, we are forced to challenge our perceptions and biases, through exposure to new ideas and dynamic dialogue with diverse partners. • This exposure and acknowledgement of different lived experiences is critical to the processes of conducting culturally responsive work and inherent to the experiential learning central to design thinking.¹¹
Collaboration	<ul style="list-style-type: none"> • Collaboration can take many forms but, at a minimum, it should account for equitable power sharing and collective decision-making. One way to formalise this, and to avoid structures that marginalise context experts or minimise their contributions, is to create a governance structure (such as a patient or community advisory board) that makes space for true engagement, rather than tokenistic inclusion or involvement.¹²
Trust	<ul style="list-style-type: none"> • While context experts may best know the needs and interests associated with their conditions or communities, many have limited experience in health research; further, some groups have a troubled and even traumatic history of interaction with researchers.¹³ • Even researchers eager to connect or convene may struggle to overcome barriers to establishing new relationships. In many cases, both context and content experts are equally unfamiliar with the norms or storms defining the others' living or working experiences. • While empathy work creates an openness to learning about others' experiences, the success of co-designed activities further depends on collaborators' commitments to building multidirectional trust.

Funders or researchers might inquire why a culturally responsive and collective research design process is important. The COVID-19 pandemic has highlighted the need to involve communities that have historically been, and continue to be, excluded from health research intended to minimise or mitigate risks, harms, and other negative impacts they experience. Community members and researchers will collectively benefit when research design processes are guided by the principles of: Representativeness, Engagement, Sense-making, Personalisation, Empathy, Collaboration, and Trust.

Design Methodology: Human-Centred Design

Human-centred design (HCD) is a dynamic approach to creating innovative solutions for complex social problems. Notably, this approach emphasises the importance of integrating diverse perspectives. Consistent with our framework, this often requires engagement of a representative group. HCD also uses collaborative processes that ensure all engaged stakeholders have equal time and status to pose their ideas, and to assume different roles or responsibilities.¹¹ Through sense-making, diverse collaborators are able to collectively create innovative solutions.

These solutions may take the form of tools, models, processes, or interventions that address a need or challenge. To arrive at this creative solution, the design team works through a series of steps (eg, *empathy, definition, ideation, prototyping, and testing*)¹¹ intended to organise their process of rapidly soliciting and integrating feedback from diverse key stakeholders, or likely end-users of the final solution. The practices associated with each step, which align naturally with principles in the RESPECT Framework, enable “design teams” to iteratively tailor their solutions in direct response to end-user feedback. This approach helps to build trust between designers and end-users, while also refining the solution and honing it into a version most likely to meet real needs. Similarly, key principles for culturally responsive research co-design naturally correspond to themes and ideas reflected in several core HCD tenets:¹⁴

- Get past your own great idea;
- Don’t be restricted by your own knowledge;
- Spend time with real people in real environments;
- Follow your users’ lead and needs; and
- Think about the whole journey of the project.

Case Example: The “Blended” Group

The Paradigm Project, convened by AcademyHealth and funded by the Robert Wood Johnson Foundation, is ideating and testing new ways to ensure HSR realises its full potential to improve individual- and systems-level health outcomes. The project was borne out of a growing recognition that the field needed to evolve to produce greater impact, respond to shifting paradigms (eg, related to data, dissemination, stakeholder engagement), and address systemic inequities in both health care and health research. To determine how best to address opportunities for health research improvement and innovation, AcademyHealth created a diverse and representative Learning Community (LC) comprising more than 100 intentionally selected volunteers. It was important to create a truly multifaceted group, to ensure that the Paradigm Project work would reflect balance across various dimensions of diversity, including both individuals’ perspectives and characteristics (eg, ages, career levels, disciplines, racial, ethnic, and cultural backgrounds, levels of education, forms of ability and disability, etc.). LC members, divided up into Design Teams (DTs), worked together over two years to co-define challenges for the field and co-develop corresponding solutions. The DTs were thoughtfully organised to feature unique combinations of content expertise and lived experience, and to recalibrate power imbalances so that all could contribute equally to the work. The process was intentionally participant-driven to such an extent that, when three of the DTs saw synergies in their work and wanted to merge, AcademyHealth adjusted the planned process and facilitated trust-building to assist their collaboration.

This newly combined team, referred to as the “blended” group, has focused its efforts on improving the health research design process by facilitating the creation of trusted, effective partnerships between diverse research stakeholders (eg, content and context experts as well as funders). Through sense-making, the group has studied pragmatic cases that incorporated the voices and expertise of under-resourced community members and resulted in powerful collective insights to advance health systems research innovation, findings, and outcomes. While these examples pointed to some progress, they also provided stark contrast to more common practices—which leave long lag times between when research is initiated, results are finalised, knowledge is shared, and change is implemented. Recognising this lag, and seeing collaboration as a conduit for creating change via culturally responsive research, more funders have started offering grants and opportunities to institutions that commit to centring patient, caregiver, and community perspectives in health research design.¹⁵

Reflection

In recent years, a community- or context-centred orientation is increasingly recognised in the HSR field as one means of producing relevant, meaningful, and replicable research. Using effective, culturally responsive design tools and practices—including human-centred design attitudes and approaches—collaborative teams can level power imbalances and navigate dynamic processes that emerge during multistakeholder co-design. They can also guarantee that the voices and perspectives of diverse partners will be fully heard and equally valued. Introduced here, the RESPECT Framework can serve as an effective guide for those seeking to adopt such a community- or context-centred orientation in their research and programmatic design work. Given widespread recognition of the changing research paradigm, and the need to involve consistently excluded and under-resourced communities in co-design, our field is ripe with opportunity for increasing sustainable and equitable research impact by ensuring the production of culturally responsive evidence.

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ACKNOWLEDGEMENTS

The authors would like to acknowledge fellow members of their “Blended” Group Design Team, and other Paradigm Project collaborators. Further, they would like to extend thanks to colleagues at AcademyHealth, The Robert Wood Johnson Foundation, and the Mazzetti (human-centred design consulting) team for their vision and leadership.

PEER REVIEW

Not commissioned. Externally peer reviewed.

CONFLICTS OF INTEREST

The authors declare that they have no competing interests.

FUNDING

None

ETHICS COMMITTEE APPROVAL

None