A call to integrate health equity into learning health system research training

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Abstract
In 2016, the Agency for Healthcare Research and Quality (AHRQ) recommended seven domains for training and mentoring researchers in learning health systems (LHS) science. Health equity was not included as a competency domain. This commentary from scholars in the Consortium for Applied Training to Advance the Learning Health System with Scholars/Trainees (CATALyST) K12 program recommends that competency domains be extended to reflect growing demands for evidence on health inequities and interventions to alleviate them. We present real-life case studies from scholars in an LHS research training program that illustrate facilitators, challenges, and potential solutions at the program, funder, and research community-level to receiving training and mentorship in health equity-focused LHS science. We recommend actions in four areas for LHS research training programs: (a) integrate health equity throughout the current LHS domains; (b) develop training and mentoring in health equity; (c) establish program evaluation standards for consideration of health equity; and (d) bring forth relevant, extant expertise from the areas of health disparities research, community-based participatory research, and community-engaged health services research. We emphasize that LHS research must acknowledge and build on the substantial existing contributions, mainly by scholars of color, in the health equity field.

KEYWORDS
health disparities, health equity, learning health system

1 | INTRODUCTION

Public awareness has recently increased about the impacts of structural racism and other institutionalized forms of oppression on healthcare, exacerbating concerns about an already troubled healthcare system. Traditional quality improvement mechanisms are inadequate for helping health systems adapt to current societal demands. As we look to re-envision the way our healthcare systems function, drawing on and enhancing Learning Health System (LHS) principles is imperative to foster more responsive and equitable systems of care. An LHS is a healthcare delivery system with embedded researchers engaged in rapid data utilization for continuous improvement efforts.1,2 An LHS approach promotes direct action in response to research findings with input from close partnerships with patients, communities, operational leaders, and frontline clinicians. Notably, these stakeholders are...
reflective of the populations working in and served by an LHS. This structure presents an important opportunity for the voices of those missed or harmed by healthcare systems to be brought to the forefront of clinical implementation and decision making. As such, LHSs have the potential to transform healthcare systems and organizational structures currently rife with inequities and producing unconscionable disparities.3,4

Recognizing the value of LHSs to transform systems of care, national research and healthcare organizations have invested in LHS-specific networks and training programs and articulated research standards to shape progress in the field.5,6 These networks and programs promote specific skills within LHS research. Specifically, in 2016, an LHS expert panel supported by the Agency for Healthcare Research and Quality (AHRQ) iteratively developed 33 separate competencies across seven domains to guide the training and mentoring of emerging LHS researchers.7 These domains are: (a) system science; (b) research questions and evidence standards; (c) methods; (d) informatics; (e) ethics and implementation in health systems; (f) improvement; and (g) engagement, leadership, and research management. More recently, the potential for LHSs to improve health inequities by enabling rapid recognition of disparities, data-driven solutions, and implementation science has come to the forefront.7,8 For example, Brookes et al (2017) discusses how LHS core values,9 such as inclusiveness and accessibility, align with health equity principles and proposes a practical framework for integrating health equity principles into LHSs.8

Despite the growing recognition that health equity must be intentionally sought to meaningfully address health disparities, formal LHS research training has not explicitly articulated how competency achievement can contribute to health equity within projects or training experiences.

While formal competency development in health equity is critical, two LHS-specific dimensions for researchers are also important to highlight. The first is acknowledging and learning from the expertise of existing scholars within the equity field. Many of these scholars are from racial and ethnic groups that have been historically, and continue to be, marginalized.10-12 These scholars have, over the last several decades, engaged in innovative and community-engaged scholarship practices. These practices, born out of a desire to address the limitations of current healthcare systems for marginalized communities, are now being adopted into the LHS framework, an evolution consistent with the developing nature of LHS research.10,13-15 Such practices include community-engaged research, in which scientists and community members collaborate as partners on a research project of interest to the community. Notably, community-engaged research is a spectrum ranging from community-informed, meaning community input on aspects of a project are sought out by researchers, to community-driven, meaning community members lead a project supported by researchers. Even as the meaning and content of LHS research has expanded and the field has increasingly recognized the importance of integrating principles of health equity in LHS research, the contributions and guidance of expert scholars who have long implemented health equity approaches remain neglected.10,11,16 We must actively acknowledge this prior work and welcome further learning to avoid perpetuating this disservice among current and future LHS researchers.

The second dimension is being aware of the ethics of working with patient groups that have been historically marginalized, both economically and socially. Meaningful LHS research necessitates questioning where health inequities could emerge or need to be addressed and identifying health equity gaps in scientific evidence. To conduct research within the context of complex health systems using appropriate study designs and analytic methods founded in health equity, LHS researchers need to consider ethical aspects of working with historically excluded, underrepresented, and marginalized patient populations. Reducing avoidable variation in uptake of research evidence and promoting its systematic implementation will ensure that all patient groups are represented in the findings and their dissemination. Effective LHS research also necessitates thoughtfully engaging with communities that experience healthcare disparities and maintaining meaningful partnerships with historically marginalized patient groups to ensure their needs and preferences are represented in the design of healthcare. This stakeholder engagement seeks to elevate the voices of patients who most often experience health inequities, with a focus on solutions that address health inequities as a key to improving healthcare overall.

As a joint effort to support the development of LHS researchers, in 2018 AHRQ and the Patient-Centered Outcomes Research Institute (PCORI) co-funded 11 centers of excellence for training future LHS researchers. One resultant center, the Consortium for Applied Training to Advance the Learning Health system with Scholars/Trainees (CATALyST) K12 program,17 engages four healthcare systems in a training consortium and has to date supported a total of eight past and current trainees (ie, “scholars”). In the absence of an established competency as a guiding principle of scholar training programs, our local CATALyST K12 program has taken a learner-centered approach to health equity-related training. With this approach, scholars are empowered and encouraged to set seminar agendas to discuss and teach health equity topics, to bring health equity experts in as mentors, to seek partnerships with health system- and community-based equity experts, to develop and share their own expertise in health equity-related research, and to center health equity in our research.

Based on our experiences, we, the CATALyST K12 cohort of scholars, see an opportunity to foster greater connection between principles of health equity scholarship and illustrate current applications to LHS research training. In this commentary, as individuals diverse in discipline, areas of focus, health system perspectives, and lived experience, we present our work and training experiences within an LHS program from an equity lens and have summarized our higher-level conclusions from our experiences for future LHS researchers and training programs. We also highlight three specific domain-focused examples of how we centered equity in our respective LHS projects, describe facilitators/enablers, specific challenges, and training gaps, and provide key recommendations for future LHS research training programs.
2 INTEGRATING EQUITY IN AHRQ AND PCORI LHS COMPETENCY DOMAINS

Health and healthcare disparities have been nationally recognized as a healthcare priority for decades, and yet many population-level health disparities have increased.\textsuperscript{18} Within the past few years, the intersection of civil rights injustices and the disproportionate burden of COVID-19 on minoritized communities has increased awareness and placed an urgency on addressing health inequities and disparities. As a result, prioritization of health equity-based funding opportunities has led to a plethora of researchers engaging in equity research.\textsuperscript{19} While the additional funding and interest is encouraging, health equity research requires competence in engaging populations facing disparities and understanding the basis of disparities as rooted in systemic discrimination. Without building these competencies, researchers newly engaged in health equity research could unintentionally cause harm.\textsuperscript{16, 20} Community-engaged researchers, who have long-standing experience in leading health equity research, often through community-based participatory research methods, have skill sets aligned with the AHRQ/PCORI LHS research competency domains. In the following sections, we highlight illustrative examples of equity-focused experiential training in our own LHS consortium - several with the mentorship of community-engaged researchers - that address identification and amelioration of healthcare disparities within three LHS competency domains. The following three examples focus on issues of structural racism, however our collective experiences have included partnering with learning health systems to address a range of experiences faced by marginalized communities; we provide examples in Table 1.

2.1 Informatics competency domain: Identification of health inequities using information systems

This LHS competency domain is “to know how to use information systems to conduct LHS research and improve patient and health system outcomes.”\textsuperscript{1} One scholar (R.Y.C.) describes their developed skills in this domain through the identification of inequities in predictive modeling.

Suicide risk prediction models have been developed and validated in various clinical settings and are now in regular use in several health systems.\textsuperscript{21-24} A concern is that clinical prediction models estimated using electronic health records (EHR) data, including prediction models for suicide risk, may perpetuate existing inequities in clinical care by presuming that historical care patterns accurately reflect clinical needs.\textsuperscript{25-30} At the same time, a strength of many data-driven machine learning methods is the ability to consider complex interactions between risk factors, an approach that may more accurately reflect intersectionality of suicide risk factors such as race, ethnicity, and gender.\textsuperscript{31,32}

A study of two prediction models for suicide death in the 90 days following outpatient mental health visits described how structural barriers to accessing quality mental healthcare may manifest as well-known statistical challenges in epidemiologic research (including risk modification and missing and mismeasured data) that impacted performance of clinical prediction models.\textsuperscript{33} This analysis identified poor performance of prediction models for American Indian/Alaskan Native and Black patients and patients without race and ethnicity information recorded in the EHR. These findings emphasize the importance of examining performance of clinical prediction models within underserved populations prior to their implementation. LHS researchers must also consider how deployment of a prediction model with differential performance may exacerbate current disparities in care. When disseminating these findings, this scholar consulted with a community-engaged researcher, clinician, and advocate with particular expertise in improving mental healthcare in underserved communities. The consultant gave guidance on how to responsibly discuss the intersection of race, suicide, and mental healthcare and avoid perpetuating racism and stigma.\textsuperscript{34}

2.2 Engagement, leadership, and research management competency domain: Engaging stakeholders in addressing health inequities

This LHS competency domain is “to engage stakeholders in all aspects of the research process and effectively lead and manage LHS research teams and projects.”\textsuperscript{1} One scholar (M.R.) gained competency in this domain through engaging patients and families in research to address disparities in dementia care.

Latinos living with dementia have higher levels of behavioral and psychological symptoms than non-Latino White people living with dementia.\textsuperscript{35} Additionally, many Latinos report unmet needs for healthcare services for information about dementia and symptoms, assistance in managing symptoms, and mental health support for family caregivers.\textsuperscript{36} One healthcare system implemented and is now testing an evidence-based virtual program that teaches family caregivers how to manage behavioral and psychological symptoms.\textsuperscript{37} However, the program was not developed with explicit consideration of Latino cultural values, beliefs, and practices.

The CATALyST scholar’s research was to engage Latino family caregivers and healthcare providers in the cultural adaptation of the program. To achieve this, the scholar’s training focused on learning participatory research approaches that foster participation and engagement of populations typically excluded from research. The scholar assembled a team of mentors that included not only traditional LHS researchers, but also a Latina researcher with expertise in community-based participatory research and in the cultural adaptation of evidence-based interventions for racial and ethnic minority populations. This mentor was instrumental in helping the scholar develop competency in this domain, particularly as it related to training in qualitative research methods and the science of culturally adapting evidence-based interventions.\textsuperscript{38,39}
### TABLE 1  Scholar experiences integrating health equity within learning health system (LHS) competency domains

| Existing LHS competency domain | Example of centering health equity | Scholar-identified equity training gaps | Scholar solutions and skills gained |
|-------------------------------|------------------------------------|----------------------------------------|-----------------------------------|
| Systems science               | Recognition that overuse of some care may disproportionately harm subpopulations that are also underserved | Need for deep knowledge of how to de-implement specific, potentially harmful overused care practices without creating further harm for underserved communities | Formal (eg, qualitative interviews) or informal (eg, patient consultancy) stakeholder feedback to design successful de-implementation interventions |
| Research questions and standards of scientific evidence | Formation of research questions that seek to understand and intervene on multilevel causes of health disparities, not merely describe differences in outcomes | Training on how to meaningfully incorporate critical race theory (and other frameworks for understanding structural inequities) into clinical and health services research | Consultation with health equity experts on study design throughout research process and on dissemination of findings |
| Research methods               | Thoughtful inclusion of race, ethnicity, gender identity, and other social determinants of health in statistical models of health-related outcomes. Adjusting for patient factors and conducting hypothesis tests to advance health equity research | Subgroup analyses and adjusting for demographic factors are expected in standard research practices, but attention to or guidance on how to justify these analytic decisions or best interpret estimates is limited | Ongoing consultation with multidisciplinary research team, seeking out expertise in appropriate methods to analyze data without further stigmatizing minoritized populations and applying a social determinant of health framework for interpretation of results |
| Informatics                    | Examining how clinical prediction models may exacerbate inequities | Training in how structural racism impacts availability and quality of clinical records data | Before model deployment, consideration of model performance in multiple populations and potential to exacerbate inequities |
| Ethics of research and implementation in health systems | Develop recruitment and data collection strategy for primary data collection of adolescents under age 18. Children are considered a vulnerable population as research subjects and are historically underrepresented in research | Few processes in place to recruit and retain individuals under 18 in research program without involving parent/guardians | Building of expertise in youth-friendly recruitment and data collection pathways that increase inclusion of youth in studies, with formal training and support from mentors |
| Improvement and Implementation Science | Incorporating user-centered design in implementation science methods, engaging marginalized populations in co-design to address disparities in care | Training and mentorship in community-engaged research | Inclusion of community organization leader on research team; mentorship from community-engaged researchers; purposive sampling to ensure engagement with underrepresented patients |
| Engagement, leadership and research management | Adapting evidence-based intervention to improve cultural relevance among an underserved population | Identifying LHS researchers with expertise in cultural adaptation of interventions | Identify mentors with expertise in CBPR, including experience outside of the healthcare and LHS research environment |

Abbreviations: CBPR, community-based participatory research; LHS, learning health system.

### 2.3  Systems science competency domain: Understanding how health systems can create or propagate healthcare inequities

This competency domain is to “understand how health systems are financed and operate and how to apply systems theory to research and implementation.”\(^1\) Through projects focused on reducing low-value healthcare, one scholar (L.S.) gained skills in evaluating how disparate health system behavior can disproportionately harm patients from marginalized subgroups.

Low-value healthcare is defined as care that provides little or no benefit to patients or carries risk that outweighs the potential benefit of care.\(^2\) Low-value healthcare is considered wasteful as both patients and the healthcare system incur unnecessary costs. The CATALyST scholar studied multilevel (patient, clinician, clinic, and organizational) factors related to receipt of low-value cancer
the growing discipline of LHS research. The application of this equity-based, systems science concept to the scholar’s work was a direct suggestion from embedded LHS mentors with longstanding experience in low-value practices and medical overuse.

The project’s findings showed that low-value colorectal cancer screening, for example, may be more likely among patients in racial and ethnic minority groups. Equitably translating these findings into de-implementation of low-value healthcare, however, has greater complexity because of the overuse/underuse (ie, double jeopardy) paradox for minority populations and risk of exacerbating cancer underscreening disparities. Contextualizing, clarifying, and providing depth to these equity-based findings and developing successful routes to de-implementation that engaged the communities at risk was largely outside the field of local expertise on this project, leading to a mentoring gap for the scholar. Successful de-implementation of low-value cancer screenings has become an ongoing effort that will extend past the formal LHS training period for this scholar. The scholar, through teaching and advice from other community-engaged researchers within the LHS training program, bridged this mentoring gap by seeking feedback for these ongoing efforts from diverse stakeholders representing patients, caregivers, frontline clinicians, and health system leadership, acquired through formal (eg, patient engagement board review, qualitative interviews, participatory decision-making methods) and informal pathways (eg, patient-partner consultation on the protocol, operational-research working groups).

3 | KEY LIMITATIONS AND CHALLENGES

The above examples demonstrate that LHS scholar training programs can enable scholars to take on health-equity focused initiatives within health systems, fostering awareness and interventions to address these inequities. These grassroot initiatives also highlight gaps that LHS training programs face in supporting scholars in developing equity-focused LHS research skills, which we summarize in Table 1. It is important to note these examples are in the context of the US health system in which patient demographic information like race and ethnicity are regularly captured and can be used for research within the context of institutional oversight of human subjects research. Outside the US, where the use of specific categories of personal data, like race and ethnicity may be limited or prohibited, external data sources may be needed to identify and target patient groups who experience health inequities.

Many scholars are interested in incorporating health equity into their LHS research and training, yet many of us found that while our LHS research mentors are passionate about equity, they did not have deep equity research expertise. In response, several of us sought mentorship outside of the LHS research community, most often among community-engaged individuals willing to collaborate with the LHS program, for example, advocates, researchers, educators, and/or clinicians with longstanding bidirectional relationships with minoritized, underserved, or underrepresented communities. While not explicitly taught, we discovered synergy in aims, approaches, and skills of these community-engaged individuals and LHS researchers, an emergent understanding consistent with the learner-led training program intent. For future programs, we see an opportunity to formally leverage expertise and learning from community-engaged research methods in the training of LHS researchers and incorporate knowledge through didactics and collaboration with community-engaged educators and researchers. Without equity called out specifically in the AHRQ LHS competency domains upon which the AHRQ- and PCORI-funded K12 LHS Research programs are based, it is difficult to identify the specific gaps and subsequent training opportunities needed. In the surge of interest in equity-focused research, we fully appreciate the real limitation that there are far fewer researchers with true expertise in health equity than can meet the mentorship and training needs of the developing LHS community. The articulation of an equity-focused competency domain in LHS research will help to identify specific training gaps and structured training opportunities that honor the history of community-engaged research as it is applicable to the growing discipline of LHS research.

4 | PATH FORWARD AND RECOMMENDATIONS

By examining examples of equity-based challenges and individualized solutions, we see clear opportunities to integrate principles of health equity into LHS research competencies and domains with accompanying training opportunities. A thoughtful and informed path forward can help adequately prepare early career LHS researchers to effectively identify and address health inequities resulting in health disparities. Our recommendations are for LHS training programs to:

1. INTEGRATE health equity throughout the LHS competencies and domains by (a) developing specific equity-focused competencies within each existing competency domain, and (b) naming health equity as a separate competency domain. Our examples show how this was accomplished within three of the seven current competency domains. Multi- and trans-disciplinary teams and innovative approaches are necessary to accomplish integration. Moreover, LHS training programs should set the expectation that scholarly projects include assessing and addressing healthcare inequities and evaluate applicant proposals accordingly. For accountability, equity-related training objectives should be documented and tracked in scholars’ formal individual development plans and communicated externally in annual program progress reports.

2. DEVELOP specific training opportunities and guidance to ensure early career LHS scholars have clear pathways to integrate equity into their work. While training opportunities may be a necessary
part of efficient exposure and scaling for LHS programs to invest in equity-focused work, they are not sufficient as a standalone solution. Moreover, while mentorship from established health equity researchers is essential, those individuals with longstanding equity scholarship or representative experiences that are relevant to the research may be overburdened by requests to provide mentorship. In these cases, we recommend scalable training opportunities. For example, funding could be set aside for scholars to attend formal, well-recognized, equity-focused training opportunities led by knowledgeable experts. Correspondingly, any within-program equity training or didactics should ensure fair and appropriate compensation to representative speakers. Scholars should also receive specific training on communicating equity-informed approaches to operational leaders at health systems, particularly those serving the most marginalized patient populations and those frequently excluded from traditional healthcare. In addition to formal training opportunities, recruitment or selection of at least one program director or associate director based on demonstrated experience in health equity-based research or education (in or outside of an LHS context) could be a formal requirement for training programs, enforced through funding mechanisms. This requirement would provide scholars at least one avenue for access to a mentor and provide a platform for equity-focused guidance and feedback through program meetings or works-in-progress. We acknowledge that training approaches must allow scholars to develop necessary skills to navigate complex ethical, legal, and social implications of engendering equity in LHS research throughout their careers. Exposing scholars to tools, frameworks, and practical exercises in critical thinking that can be applied to a dynamic health system and social landscape over time is essential. One example approach is to teach equity principles using Problem Based Learning (PBL). PBL asks learners to not only draw on current knowledge but to identify what knowledge is needed to address complex issues relating to numerous aspects of societies. In this approach, no one right answer may exist. Instead, using a case-based approach, learners cultivate a deep understanding of the many considerations within a problem, further developing critical thinking skills. This process is then used to propose varying approaches to address different aspects of the problem. Applied in an LHS equity context, this can encourage recognition that there is no one solution to a problem and facilitates the consideration of a range of stakeholders in the development of varying solutions as appropriate.

3. Evaluate the commitment to health equity in LHS research through top-down and bottom-up program evaluation. LHS scholars, training programs, and funders should hold themselves accountable to their commitment to health equity. Scholars should regularly reflect on achievement of learning and project goals related to health equity in formal individual development plans. Applying the LHS learning cycle approach (Knowledge to Performance, Performance to Data, Data to Knowledge), training programs and funders should conduct iterative program evaluations with standards established according to a health equity framework in order to continuously improve their approach to equity over time.

4. Bring forth the wisdom and expertise that has been foundational to the field of LHS research in the form of community-engaged health disparities research. Scholars and training programs need to bring in mentors and consultants who have been steeped in this work and amplify their expertise with structural support and funding. LHS training programs should seek to recruit scholars with diversity in discipline and lived experience to ensure a range of lived experiences are represented and reflected in projects and training goals. Program leaders may consider developing longitudinal, mutually beneficial partnerships with community or representative bodies providing collective knowledge and skills. To allow the emergence of this knowledge, research methodologies used by scholars should ensure shared power dynamics such as participatory action research and human-centered design approaches.

Training programs need to support and train scholars to meaningfully and responsibly engage with historically marginalized patient groups to ensure their needs and preferences are represented in the design of healthcare. Programs and scholars should also ensure that contributing partners are adequately and equitability recognized as co-authors in dissemination of LHS research through peer-reviewed publications and conference presentations.

5. Conclusions

As the field of LHS research continues to evolve and acknowledge the central role of health equity in improving health systems and communities, LHS research training must be equipped to operationalize and integrate health equity principles across the continuum of training and research activities. Our perspectives offer concrete examples of scholar-identified opportunities to center health equity within their LHS competency building. Based on these perspectives, we make four recommendations for the LHS training programs—to integrate health equity throughout LHS competencies and domains, develop training equity opportunities and mentorships, regularly evaluate health equity incorporation, and bring forth existing LHS wisdom and expertise in health equity. Future efforts to quantify and evaluate the integration of health equity principles into LHS research and training are also needed.

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Conflict of Interest

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