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The Promise of Precision Population Health

Reducing Health Disparities Through a Community Partnership Framework

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Keywords

• Precision medicine • Population health • Precision population health
• Precision public health • Community partnerships • Community engagement
• Community-based participatory research • Health disparities

Key points

• Precision medicine approaches provide opportunities to understand health and disease across populations and to target interventions that will simultaneously improve health and reduce health disparities.

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Health care in the United States is characterized by extremes, with novel scientific breakthroughs and state-of-the-art, specialty care juxtaposed by some of the worst health outcomes [1]. The United States ranks lowest in maternal mortality, infant mortality, and life expectancy compared with other high-income nations and also has the highest total spending on

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- Inclusion of community members as experts is foundational to the promise of precision population health, allowing an accurate understanding of the root causes of poor health and the identification of effective interventions.
- The authors provide a framework that illustrates the iterative interplay between the key elements of precision population health and community-based participatory research to achieve health equity.
- Institutions have a critical role in precision population health by providing the infrastructure to support and sustain community engagement and by carefully monitoring and balancing ethical implications.

health as a percentage of the gross domestic product. Health outcomes are not evenly distributed across US populations, because there are large differences by race and zip code. As a stark example, a baby born in 1 neighborhood can be expected to die as much as 25 years earlier than a baby born just a few miles away [2]. In addition, infant mortalities are twice as high for black mothers compared with white mothers with socioeconomic status accounting for only part of the difference [3].

In the United States, child health disparities are widening largely due to factors outside the scope of traditional medical care. As a result, health care, health care delivery, and research practices are developing novel mechanisms to improve health outcomes. For example, pediatric practices are piloting ways to screen and integrate care for the social determinants of health [4,5], and health systems are moving toward value-based care and population-based metrics [6]. However, there is no clear algorithm for tackling the historically and systemically embedded roots of health inequities. Improving the health of a population with an equity lens is complex, requiring health and academic institutions to create and transform different approaches to fulfilling their mission; these approaches must inevitably include multisector collaboration, integrated data systems, and policy changes [7].

Precision medicine has been touted by many as an approach that can improve health by tailoring prevention and treatments to individuals [8]. Tailoring is not new, but the advent of "big data," with large-scale biological databases, the ability to characterize patients across multiple biological domains, and the computational efficiency to consider multiple biological characteristics in a way to influence clinical decision making and practice, is the promise articulated by those espousing precision medicine [8]. Precision medicine has been criticized by some who argue that genomic and other "omic" variation leveraged in precision medicine are unlikely to address the major sources for poor health and variability in health outcomes observed in the United States [9]. Another criticism is that a focus on precision medicine will funnel resources away from addressing important social determinants of health that make larger contributions to poor health outcomes observed in the United States [10]. Without dismissing these critiques, others have argued that the precision

approaches to understanding health and disease can also be applied to broader public and population health endeavors. These arguments have focused on broader concepts of precision health (rather than just precision medicine) and even have included notions of precision public health or precision population health (PPH). Those who have advocated for these views note that assuring diversity in efforts at biological characterization is essential for good science; integrating social, environmental, and behavioral determinants with the biological determinants of health will increase the ability to tailor prevention and treatments; and computational and technological advances can be applied effectively to public health problems as well [11]. Here, the authors embrace these notions under the framework of PPH and explore those principles of community engagement that will be necessary for assuring that current precision advances can be effectively applied to achieving improved health for the population.

In fact, the premise and promise of PPH suggest an inherent research practice based on community engagement whereby those in a population are active participants in setting research priorities, collecting and submitting individual data as "citizen scientists," determining relevant data to analyze, and offering explanatory models for findings [11]. However, descriptions of PPH do not clearly integrate well-established research frameworks that include community, such as community-based participatory research (CBPR). Instead, if mentioned in PPH efforts, community involvement is raised in the context of the importance of including diverse populations and disseminating interventions [12]. True community partnership using approaches such as CBPR will allow for the creation of targeted, precise interventions that understand the culture and relationships required for sustained health improvement.

In this article, the authors establish the context of precision medicine in improving population health, the history of community-based participatory research, and the application of CBPR to reducing health disparities and provide a framework for integrating the important and promising practices of PPH and community-based participatory research to achieve health equity.

PRECISION MEDICINE AND POPULATION HEALTH

Advancements in biomedical science, such as the mapping and sequencing of the human genome and proteomics, have led to an explosion of information and a new understanding of rare and more common diseases at an individual level [13]. For example, the subtyping of pediatric cancers has allowed for nuanced treatment protocols and improved outcomes [14]. Similarly, hundreds of genetic mutations are linked to autism, potentially explaining the wide spectrum of the disorder and offering the possibility of targeted treatments [15]. Although the concept of precision medicine has been in use for decades, including practices such as blood typing and newborn screening, the term "precision medicine" evolved in the past decade to describe "an emerging approach for disease treatment and prevention that takes into account individual variability in genes, environment, and lifestyle for each person" [16].

Widening health disparities are in stark contrast to the rapid evolution of precision medicine sciences. Despite the opportunity for better outcomes via more precise health care, fundamental health indicators like infant mortality and life expectancy are vastly different between populations [17]. There is increasing recognition of the health impact of the "conditions in which people are born, grow, live, work and age" or the *social determinants of health* [18]. With medical care estimated to account for only 10% to 20% of the modifiable contributors to good health [19], health systems are developing innovative approaches to address the social determinants of health and improve health outcomes of populations.

The application of precision medicine to improve populations has been in existence for decades. Newborn screening, for example, allows for the early identification, diagnosis, and treatment of a growing number of genetic disorders and is a public health program that is mandated throughout the United States. More recently, the application of precision medicine to the social determinants of health is emerging as a potential method to reduce health disparities [20]. For example, using data on asthma admission rates, researchers have been able to link asthma "hot spots" to specific public housing properties, identifying exacerbating environmental conditions, such as extensive mold and cockroach infestations. The medical treatment, in this case, was not access to health care or a specific pharmacologic intervention; rather, the "prescription" was better housing conditions. There is incredible power in the ability to analyze data to accurately and efficiently connect the "dots" and reveal the full landscape of multiple, individual experiences.

PPH has 4 general components: the collection of data for disease surveillance and detection, the prediction of risk, the targeting of interventions, and an understanding of the disease. Disease surveillance and detection require the accurate collection and review of data and can be applied to a gamut of conditions, including infectious diseases and environmental hazards. Technology, such as mobile phone and GPS data, enhances surveillance by better tracking affected individuals [21]. Enhanced surveillance and detection of conditions also allow for the possibility of more accurately predicting health risks in subpopulations and individuals. Enhanced surveillance and detection allows for the identification of subpopulations at risk for conditions, including infectious disease outbreaks [21], higher asthma admissions [22], premature birth [21], and "social" conditions, such as justice involvement [23]. The refined detection of conditions and prediction of risk do little to improve health if not paired with the application of effective, targeted interventions. These interventions are appropriately broad in scope given the range of risks being identified and include the early treatment of inborn errors of metabolism identified from newborn screening to the concentration of social programming to community "hot spots" for juvenile justice involvement. These 3 attributes of precision public health: surveillance and detection, predicting risk, and targeted interventions, also allow one to understand disease in new and different ways and to provide a better grasp of how to diagnose and treat diseases as varied as diabetes, influenza, and preterm birth [24].

An accurate and applicable understanding of disease also requires that PPH efforts collaborate with community stakeholders and that these collaborations acknowledge the deeply entrenched and systematically reinforced mistrust that communities, particularly those most impacted by health inequities, have of academic and health institutions. Fortunately, the field of research has developed approaches to involve community stakeholders that can serve as powerful guides for the practice of precision medicine in improving the health of populations.

COMMUNITY RESEARCH PARTNERSHIPS AND REDUCING HEALTH DISPARITIES

There are several approaches that support a spectrum of community involvement in research, including community-engaged research and participatory action research. The authors recognize that not all PPH efforts can support the ideal of equal partnership in the cocreation of research across the research process. However, the authors also think it is critical to highlight the far end of the partnership spectrum as the optimal approach to reducing health disparities [25]. Community-based participatory research (CBPR) is a collaborative research approach whereby academic and community stakeholders are equal partners across the spectrum of the research process [26–28]. In the past 20 years, CBPR emerged as a research framework combining ''action'' and ''participatory'' research processes with the goal of improving the lives of those targeted by the research. The ''action'' approach involves a cyclic process, incorporating action, reflection, problem solving, and decision making between partnerships [29]. ''Participatory research'' [30] emphasizes the lived experience, particularly of oppressed social groups, and recognizes issues of power and privilege. Specifically, CBPR combines the importance of coparticipation, with self-awareness of issues like power and privilege. There are 4 general expectations of CBPR projects: (a) capacity building, (b) colearning, (c) shared benefits among partners, and (d) reduction of disparities [26,27,31].

Principles in CBPR have been elaborated on by past research and vary in their application to each study [32]. *Capacity building* is aimed at creating the infrastructure needed to plan for future steps (eg, staffing, networking, and training). *Colearning* is defined as the process of exchanging knowledge (eg, data interpretation) and skills (eg, data analysis) between institutions and community members. *Shared benefits* are when the institution and partners involved both profit from the research, including the results that can be reaped. Results should further research agendas and translate into action for the community. Finally, and a particularly important principle, is that CBPR should aim to reduce disparities. In other words, researchers should aim to partner with communities to reduce the differences various neighborhoods, ethnic populations, and socioeconomic statuses experience in health outcomes.

CBPR provides the potential to include diverse community voices and build infrastructure with key community partners for sustainability. However, in

communities most impacted by inequities, CBPR research faces challenges of careful navigation in power and privilege [26,27]. First, to reduce health inequities, it is essential to consider the power dynamic and assumptions introduced into the investigation. Researchers may have a "perceived power base" because they serve as experts [26]. Physicians, regardless of whether they are researchers, may also function as a perceived power base if they are seen as experts. Second, physicians should be aware of the assumptions they may bring to understanding the causes of poor health outcomes and the drivers of individual behavior, especially given the growing percentage of medical students who come from the highest levels of family household income [33]. Third, in small communities, investigators have to be cognizant of the ramifications from misrepresenting their expertise, because community members may rely on their word in the absence of local resources. Last, future investigators should also consider that power and bias issues brought from university or hospital affiliations may extend to other stakeholders. Selecting community stakeholders that are nonresidents, from highly educated fields, or part of the ethnic majority may all pose challenges in gaining an honest community perspective [34], and stakeholders may not be community residents. With heightened awareness of their own biases, academics, physicians, and other stakeholders have the opportunity to combine community expertise with their own skill sets and create relevant change to reduce disparities.

PRECISION POPULATION HEALTH AND COMMUNITY-PARTNERED RESEARCH

The intentional integration of community expertise into the practice of PPH offers a potent, complementary approach to reducing health disparities by creating tailored interventions with the community as partners. Although precision medicine uses databases to empower one to identify populations at risk for and affected by disease, approaches such as CBPR provide the mechanism to understand the nuances of associated risk factors, root causes, and effective interventions. Indeed, without using approaches such as CBPR, PPH efforts risk making false assumptions about research priorities, the data to examine, the interpretation of results, and effective interventions.

The authors' belief is that true partnerships with community should be an essential core competency of PPH at every step. They propose a PPH framework (Fig. 1) with the central goal of reducing disparities while understanding disease. To achieve this goal, the PPH framework embeds CBPR within the PPH disciplines [24] through an iterative, progressive set of stages that evolves via lessons learned and layers of relationship and trust building. To provide context, the authors discuss the PPH framework using the common childhood condition of asthma.

SURVEILLANCE AND DETECTION

Surveillance and detection require infrastructure for researchers and community members to gather the most useful data relevant to the desired health

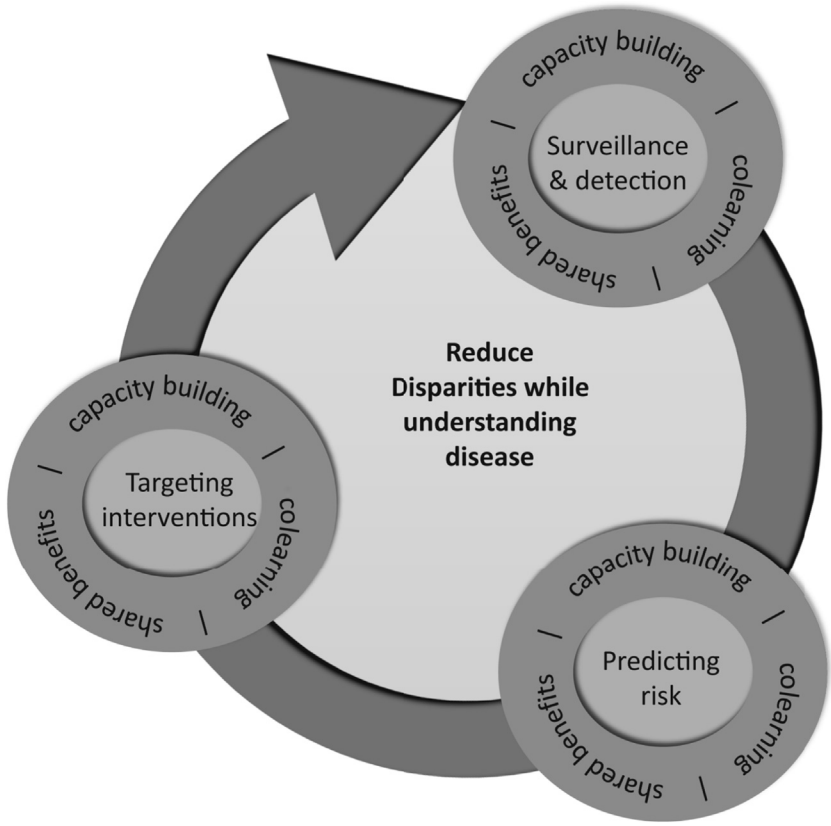

Fig. 1. PPH framework.

outcomes. Questions regarding the populations of interest, useful geography (eg, neighborhoods vs zip codes), and key assets (eg, housing, schools, pharmacies) are best answered in partnership with the community to ensure that the platform built and implemented is relevant and effective. Initial partnerships between researchers and the community could begin with an offer of *capacity building*. Capacity building could include building a biomedical understanding of asthma and enhancing knowledge about different data collection tools, like geocoding and mapping and their respective strengths and limitations. In turn, both researcher and community members work together and begin a *colearning* process to identify common priorities. Each can draw on their spheres of expertise and, together, identify how these assets do or do not work together to mitigate asthma's impact on children. Future linkage of data between disparate data sources, such as health, schools, housing, and pharmacy sectors, for full surveillance detection will ultimately require that mutual benefits to researchers and community stakeholders are compelling and clear.

PREDICTING RISK

The second stage in understanding disease involves developing a better understanding of its determinants, which includes the CBPR principles of *capacity building*, *colearning*, and s*hared benefits*. For instance, through *capacity building*, communities can improve prediction of asthma risk by sharing archival data and current data collection tools. In addition, capacity building can help build community trust and enrollment in broader surveys, in-home sampling of environmental triggers, or participation in air sampling techniques. Such efforts would help PPH better detect the neighborhoods most at risk for asthma by improving survey response rates, by targeting a broader range of the population, and by increasing the validity and richness of data collected. *Colearning* can also improve risk prediction because the community can impart knowledge on why certain neighborhoods might be more at risk (eg, cockroach infestation) or point to risks that might be missed (eg, idling school buses). Both researchers and community members can experience *shared benefits* in asthma research. Results from the data can help researchers understand current data trends and gain fresh insight into why some communities are doing better than they predicted (eg, a "bright spot"). Community members can better understand which children may be at higher risk and why and be better positioned to inform city developers in the future (eg, school placement and walking routes that avoid high-traffic areas).

TARGETING INTERVENTIONS

In the final stage of understanding asthma, *capacity building*, *colearning*, and *shared benefits* are critical to successfully targeting interventions. The community can help *capacity building* by linking researchers with venues that would be most receptive for intervention. Alternatively, they may be able to share staff and funding for delivering the asthma intervention. Researchers can teach community members methods in which to manage and treat childhood asthma. In contrast, the community can share with the researchers the barriers (eg, transportation) to receiving that treatment. Targeted interventions also encompass shared benefits in their results. For instance, results may demonstrate that an intervention had different effectiveness across ethnic groups even though the individual patients were in the same neighborhood. Such results help researchers understand that interventions may need to be adapted to certain groups within a community. These heterogeneous effects from an intervention also help the community understand the anticipated effectiveness across their community to aid planning for future resource investment.

In the PPH framework (see Fig. 1), each PPH activity undergoes a distinct process by which CBPR concepts are embedded to enhance the quality of data collection and use of data through partnerships. More importantly, each PPH activity should be thought of in a cyclical process for continued refinement. Once a targeted intervention is disseminated, continued surveillance checks should be made to monitor the progress of the disease and whether disparities are being mitigated. If progress is not made, the partnership should

reassess the current community needs, data validity, and the chosen logic model. When successful, lessons can be learned from the PPH approach to help predict risk and scale target interventions in other communities based on generalizable elements.

THE ROLE OF ACADEMIC INSTITUTIONS

Academic medical centers and university systems are beginning to create infrastructures and programs that align their precision health sciences, such as epidemiology and data analytics, with community-based research priorities. Distinct from the community outreach goal of recruiting diverse study populations or the patient advisory council goal of improving clinical performance, the idea of community advisory research boards is to partner with communities "upstream" in the research process and to cocreate research priorities and approaches. Academic institutions that have a mission to improve the health of their local environment should adopt the PPH framework for strategic planning and scientific development. Integrating the PPH framework will help to build trust and engage community members as partners rather than subjects. As described above, this approach is most authentic and effective in addressing health disparities when partnerships are developed before research design and the establishment of hypotheses. However, these partnerships require institutional culture change, infrastructure, and support [7,35].

For example, the University of Illinois Cancer Center has combined their population level data on cancer outcomes in the city of Chicago with the creation of a "patient brigade." By using CBPR and patient outcomes research, this patient brigade integrates itself with each research and community initiative in search of better treatments and potential disease cures. Similarly, with funding from the Patient-Centered Outcome Research Institute, the University of California San Francisco (UCSF) Child Health Equity Initiative launched the Transforming Research as Usual for Equity (TRUE) program to build institutional infrastructure for sustained community-partnered child health research. Over 2 years, TRUE developed consensus around child health research priorities for San Francisco. These priorities were then disseminated to more than 100 local, multisector stakeholders to inform their efforts to improve child health and reduce health disparities. These programs serve a critical role in providing the institutional infrastructure to support community-partnered approaches to PPH efforts.

In addition, motivated in part by the move toward value-based care and accountable care organizations, health systems and academic health institutions also are increasingly developing units to improve the health of populations. Southern Illinois University School of Medicine, a community-based medical school in Springfield, Illinois, has recently launched an entire department dedicated to bridging population health analytics and CBPR. Organized around Divisions of Epidemiology and Biostatistics, Human and Community Development, and Health System Science, this Department of Population Science and Policy is built around a social mission that recognizes that data should

be collected by the people and for the people to design sustainable community-driven programs and interventions that improve the health of children and families. Similarly, UCSF has had a long-standing interest in PPH as a part of its precision medicine initiatives and has fostered discussions about how advances in the current environment can be used to improve prevention, population health, and health equity [36]. In 2016, UCSF hosted the Precision Public Health Conference sponsored by the White House Office of Science and Technology Policy and the Bill & Melinda Gates Foundation focused on the First 1000 Days of life. UCSF also has an ongoing Population Health Data Initiative that includes collaboration between the UCSF Health Office of Population and Accountable Care and various units in the UCSF School of Medicine on the role of data to improve population health.

Precision population health framework: ethical considerations and challenges

With the PPH framework (see Fig. 1), the authors aim to highlight the critical role of community partnerships in PPH efforts to reduce disparities and understand disease. Their proposed framework, however, does not avoid some of the pitfalls of PPH. The potential for data misuse forces researchers to acknowledge and consider the ethical issues of their work. Implications exist for health information privacy, data security, informed consent, and even discrimination [37].

The current technological infrastructure allows for the storage and linkage of unprecedented amounts of data from an increasingly diverse array of sources, including an individual's genetic code as well as their smart devices, text messages, credit card purchases, online activity, electronic medical records, use of public programs, and global positioning system data [38,39]. The linking of this information offers researchers and private and public interests unique opportunities to understand attitudes, behaviors, and disease states. However, when consenting to the sharing of data, researchers and participants alike are not likely to understand the extent of data being shared or the full implications of sharing the data [38–41]. Greater attention will need to be placed in understanding the agendas of both the researchers and funders. As the ability to understand the nuanced behaviors of certain communities and even certain segments of those communities becomes clearer, the potential exists to use this information to stigmatize or bias vulnerable communities in subtle ways that are not protected by the existing antidiscrimination laws and regulations. For example, interventions or services could be targeted for or against individuals living in certain zip codes, which could be proxy measures for protected classes such as race or religion. "Big data" also poses risks to individuals by uncovering potentially negative or discriminatory information that may not have even been considered in their initial intent of the research. For example, case managers review individual purchase data from electronic benefit transfer cards to identify fraud. Otherwise data are used to create algorithms to predict a child's risk for maltreatment, including prior referrals to child protective

services, which introduces substantive risk in perpetuating systemic biases, racism, and inequities [37].

Finally, PPH requires that academic health institutions substantively commit to new institutional practices, such as research ethic boards and institutional review boards that are equipped to handle the complexities of "big data" and PPH endeavors. In addition, community partnerships to support PPH require a long-time horizon with sustained institutional investments. Traditional models of investigator-driven research grants are generally counterproductive, perpetuating short-term goals and challenging environments for building community trust [35]. To impact the health of populations, institutions need to invest in a sustainable infrastructure to support capacity building, colearning, and shared benefits that is on par with investments made to the traditional tripartite mission areas of patient care, research, and education.

MOVING FORWARD

The evolution of applying precision science to improve the health of populations offers the exciting possibility of addressing health inequities amid the growing evidence of widening disparities. This promise of PPH requires the collaboration of multiple sectors and, in particular, the partnership of communities most at risk for and most impacted by health inequities. The authors believe that established research practices for community collaboration, such as CBPR, should serve as core competencies of precision health efforts to reduce disparities and understand disease. PPH should also pay heed to important lessons and barriers to academic and multisector partnerships that can perpetuate inequities. Research and health institutions also must invest in infrastructure to sustain community-partnered precision health. The PPH framework illustrates the integration of CBPR into common PPH activities and highlights the iterative learning and implementation nature of this approach. It is the powerful combination of precision science with approaches like CBPR that deepen the understanding of the root causes of disparities and that can lead to identifying and addressing systemic inequities.

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