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Community Health Models

An Attempt to Address Emerging Challenges
and Technology in Diverse Settings

Edited by Bishan Swarup Garg



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Meet the editor



Dr. Garg, MD, Ph.D., is a Secretary of the Kasturba Health Society and an Ex-Dean of the Mahatma Gandhi Institute of Medical Sciences, Sevagram. He received the Best Teacher award from the Maharashtra University of Health Sciences, Nashik, for the year 2005/2006, Commonwealth Medical Fellowship for one year at the Liverpool School of Tropical Medicine, UK, in 1989-1990, Fellowship of the National Academy of Medical Sciences, Fellowship of the Indian Association of Preventive & Social Medicine and Fellowship of Indian Public Health Association. He was the President of the Indian Association of Preventive & Social Medicine in 2002. Various funding agencies have awarded Dr. Garg more than 90 research projects. He served as a consultant to the WHO and to various international and national agencies on public health issues. Current Chairman, Programme Advisory Committee of the National Institute of Health and Family Welfare, New Delhi, and also President, Voluntary Health Association of India. He was Elected Emeritus Professor of Community Medicine by the National Academy of Medical Sciences (India) for 2026-2030.

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Preface

In the era of globalization and market economy, due to economic polarization, rural, marginalized, and persons with very weak socio-economic status are being pushed towards poor health status, which leads to poverty over the years. There have been several attempts globally to develop the Community Health Action Model, with full and active participation of community members, to improve community health status in a participatory manner. All these models have worked very well across different settings in a project mode, where action is taken within the overall vision and philosophy of the specific project/organization. However, there have been issues with their replication in program mode or with their generalizability.

In the 21st century, new health challenges have emerged due to the resurgence of communicable diseases, the emergence of new communicable diseases, and the increasing burden of non-communicable diseases, especially in the developing world. At the same time, environmental degradation and climate change have emerged as major challenges to public health in both developed and developing countries. In these circumstances, the emerging health technology, digital and mobile health, has emerged as a ray of hope for addressing health challenges in more appropriate, affordable, and acceptable ways, especially for marginalized, rural, and tribal populations in the developing world. In this scenario, it has been imperative to develop the community health model from different settings- community as well as from health care settings at different levels.

The book is an attempt to diversify traditional community health action models across different levels of health care settings, with the application of new technologies in a participatory manner involving both providers and patients/community members. The book has been divided into three sections: *Partnering with Community and Health Governance*, *Emerging Community Health Challenges and New Technology*, and *Community Health Models in Diverse Settings*.

The first section has four chapters. The first chapter has covered the policy transformation from the Neo-Liberal model to the Fourth Transformation (2018-24). The chapter concludes that this new framework, while aiming to correct past flaws, remains constrained by historical path dependencies and faces monumental challenges in ensuring equitable, high-quality healthcare access for all. The second chapter includes a set of interrelated goals, such as no poverty, no hunger, good health and well-being, quality education, gender equality, and reduced inequalities. The third chapter has examined models of community collaboration and partnership that move beyond extractive engagement toward equitable participation, highlighting principles of shared power, accountability, mutual benefit, transparency, and trust. The fourth

chapter has discussed policy implications for strengthening the integration of these models into national health systems. It presents recommendations aimed at scaling up and sustaining them in contexts of high social vulnerability.

The second section of the book covers emerging community health challenges and new technology, with three chapters on digital technology, climate change, and mental health. The first chapter proposed framework offers a replicable model for improving collaboration, reducing clinician burden, and optimizing outcomes in diverse primary care environments. The second chapter has linked advocates for resilience building through co-produced, equity-driven frameworks that integrate lived experience and experiences from intersectoral collaboration. Further, by linking public health practice with climate resilience and migration-informed strategies, the chapter discusses inclusive, adaptive, and justice-centered community health systems in the face of growing global challenges. The third chapter of this section supports consumer-run mental health services as valuable and effective, and offers the greatest opportunity for volunteer and paid work and skill development, from payroll to driving to reception to arranging furniture.

The third section comprises three chapters on diverse clinical settings. The first chapter concluded that patients' negative attitudes towards patient education, language barriers, and the lack of appropriate facilities negatively impacted their education. As a recommendation, policymakers can use this information to enhance the effectiveness of patient education programs in Abu Dhabi. The second chapter aims to guide the balancing of scientific objectives with equitable care in global health research. The third chapter challenged the reader to think beyond simplistic 'plug and play' POC testing enabled by technological advancements and to implement real-world solutions to minimize pre-analytical, analytical, and post-analytical risk. This information will help optimize POC test accuracy, accessibility, and affordability, underpinning larger-scale models to improve community health and well-being.

The present book covers the emerging challenges and issues in community health in diverse settings, from the field to clinics, to promote community health globally and address the challenges in health, wellness, and equity. I hope the book will provide readers with a new perspective on emerging community health. I am thankful to all my colleagues and family members for their support in editing the book. I am thankful to IntechOpen for the opportunity to edit the book. My special thanks to Ms. Kristina Kardum Cvitan, Publishing Process Manager, for extending her valuable support.

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Section 1

Partnering with Community and Health Governance

Chapter 1

A Critical Analysis of Health Policy in Mexico from the Neoliberal Model to the Government of the Fourth Transformation

Juan Manuel Lira Romero

Abstract

This chapter critically examines the complex transition of Mexico's health system under the Fourth Transformation (4 T) administration (2018–2024). Using a public policy framework centered on the concept of “path dependency,” the analysis identifies the structural continuities and ruptures between the previous “neoliberal model,” embodied by *Seguro Popular* (SP), and the new state-led paradigm. The key finding is that the 4 T's reform constituted a radical ideological and discursive rupture mounted on a profound structural and operational continuity. The chapter demonstrates how the initial, chaotic implementation of the Institute of Health for Well-being (INSABI) and the subsequent pragmatic pivot to the IMSS-Bienestar model reveal that political voluntarism is insufficient to reverse decades of institutional inertia. Despite changes in administrative schemes, the system remains deeply fragmented and underfunded, failing to solve the persistent gap between nominal coverage and effective access to care. The chapter concludes that the future of Mexico's health system depends not on further institutional demolitions but on the sustained building of interinstitutional bridges and the consolidation of a fiscal pact to guarantee universal, high-quality healthcare.

Keywords: health system reform, fourth transformation (4 T), neoliberalism and health, path dependency, Seguro popular, Mexican health system

1. Introduction

The guarantee of the right to health is one of the fundamental promises of the modern state and an irreplaceable pillar of social development. In Mexico, this aspiration has been the epicenter of intense debate and profound reforms that have consumed enormous political capital, particularly during the administration of the Fourth Transformation (4 T), led by President Andrés Manuel López Obrador (AMLO) (2018–2024). This administration came to power with a mandate for change and a decisive diagnosis: the preceding “neoliberal health model,” blamed for the

marketization of health, had not only failed in its promise of universality but had fundamentally become a vehicle for corruption and inequality.

This chapter critically examines this complex and turbulent transition. The objective is to identify the structural continuities and ruptures between the neoliberal approach and the model advanced by the 4 T, considering its key dimensions: institutional, concerning the system's architecture and governance; financial, related to the sources and flows of resources; and social, pertaining to effective access and equity. It will be argued that, beyond the powerful discourse of a total break, the administration's health policy has been characterized by a complex process of ideologically dismantling previous structures, followed by a pragmatic and often improvised recentralization. While this new model seeks to correct the failures of the past, it faces its own monumental challenges in guaranteeing equitable, high-quality access.

To understand this dynamic, it is crucial to recognize the two structural flaws the new government aimed to resolve. First, a historically fragmented health system that, since the mid-twentieth century, created different "classes" of health citizenship: a first-class category for formal workers enrolled in social security and a second-class one for the uninsured population, dependent on under-resourced public assistance services. Second, a neoliberal model (1983–2018) that attempted to address these gaps by separating functions and creating public insurance through *Seguro Popular* (SP). This approach, however, introduced market logic and complex decentralization whose outcomes in financial protection and quality of care are a central focus of our analysis.

Faced with this landscape, the 4 T proposed a complete discursive and programmatic rupture. This materialized in the elimination of *Seguro Popular*—an act justified under the banner of fighting corruption—and its replacement by two successive models: first, the short-lived Institute of Health for Well-being (INSABI), and after its failure, the current centralization project operated by IMSS-Bienestar.

2. Historical evolution of the Mexican health system

The current configuration of any health system is incomprehensible without an analysis of its historical trajectory. In Mexico's case, the fragmentation and inequality that have characterized it are not accidental outcomes but the consequence of a deliberate process of institutional construction, known in public policy theory as "path dependency." Decisions made at critical junctures in the past created a path from which it has been exceedingly difficult to deviate. This section traces the foundational milestones that forged a segmented system, establishing the structural conditions that subsequent reforms would seek to resolve (**Figure 1**).

2.1 The foundations: A Bismarckian model for formal Mexico

The design of Mexico's modern health system was consolidated in the mid-twentieth century, at the height of the "stabilizing development" model, or the "Mexican Miracle." In this context of industrial growth and the consolidation of a strong postrevolutionary state, a social insurance model of Bismarckian inspiration was adopted, characterized by its financing through mandatory contributions linked to formal employment. The first and most important pillar was the creation of the Mexican Social Security Institute (IMSS) in 1943. Conceived as a social pact between the state, capital, and organized labor, the IMSS offered a comprehensive package of benefits—medical care, pensions, and other social services—financed tripartitely by



Figure 1.
 Model of the historical evolution of the Mexican health system. The diagram presents a model of the historical and prospective stages of the health system, from its Bismarckian legacy and the neoliberal paradigm to the “containment stage” (2018–2024) of the Fourth Transformation, which seeks to lay the groundwork for a future transition and consolidation of the model. Source: Own elaboration.

private sector workers, employers, and the state. This arrangement, while innovative, institutionalized an indelible link between formal employment status and access to quality healthcare.

This logic of segmentation was deepened and reinforced 16 years later with the creation of the Institute for Social Security and Services for State Workers (ISSSTE) in 1959. This new institution replicated the IMSS model but was exclusively for public sector employees. With this, the state not only consolidated fragmentation but also created a parallel system for its own workers. This design, in addition to creating exclusion, tied the system’s financial health to economic cycles—leaving it vulnerable during recessions and unemployment—and granted considerable power to union leadership in the governance of these institutions.

By the 1960s, Mexico's health landscape was clearly divided: on one side, two powerful social security institutions serving the formal sector of the economy, operating under an insurance logic. On the other hand, there is a vast majority population of informal workers, peasants, and the unemployed. This second group fell under the responsibility of the then-named Secretariat of Health and Assistance (SSA). Unlike the IMSS and ISSSTE, the SSA operated under a public assistance logic, not as health insurance. Its services, financed directly by an insufficient general budget, were characterized by a chronic scarcity of resources and infrastructure. This approach conceived of health for the poor not as an enforceable right but as a handout or an act of state charity, subject to budgetary discretion. Its focus was primarily preventive and on public health (vaccination campaigns, sanitation), with a very limited capacity for the specialized and high-cost care that was offered in social security hospitals, thus consolidating a de facto two-tiered medical system in the country. This duality cemented an inherently inequitable system, with enormous differences in per capita spending between an insured and an uninsured citizen [1].

2.2 The turning point: The unfinished decentralization of the 1980s

The context of the 1980s debt crisis—the so-called “lost decade”—and the influence of the “Washington Consensus” economic agenda, which promoted state reduction and the decentralization of public services, marked a turning point. In this environment, a constitutional reform was carried out in 1983 that, paradoxically, elevated the right to health protection to a constitutional level for all Mexicans for the first time. However, the strategy to materialize this universal right was not the unification of the system but, on the contrary, its administrative decentralization.

Official discourse promoted the reform as an act of democratization and federalism, but in practice, the transfer of responsibilities was not accompanied by a robust and equitable financing formula to guarantee operations. Driven by this logic, decentralization involved transferring the infrastructure and operation of SSA services to the 32 states, giving rise to the State Health Services (SESA in Spanish). Far from resolving the original fragmentation between the insured and uninsured, this process atomized it even further. The result was the creation of 32 subnational health systems that were heterogeneous and profoundly unequal, with vast disparities in their technical, financial, and managerial capacities. Thus, the quality of public health became a geographic lottery: a citizen in a state with greater resources of its own could access better services than another in an entity with precarious finances [2].

By the end of the 1980s, the Mexican system was a complex and inefficient institutional archipelago: two large federal social security systems, parastatal systems (for state-owned oil and military enterprises), 32 state systems for the uninsured population with disparate financing and capabilities, and a growing private sector. This structure—deeply segmented, inequitable, and difficult to govern—became the main object of criticism and the problem to be solved for subsequent waves of reform, starting with the neoliberal model that, in the following decade, would attempt to bring order to this chaos through a financial approach, as analyzed in the next section (**Figure 2**).

3. The “neoliberal model” (1983–2018): Design and results

As established in the previous section, the decentralization of the 1980s resulted in an inefficient and inequitable institutional archipelago. Faced with this

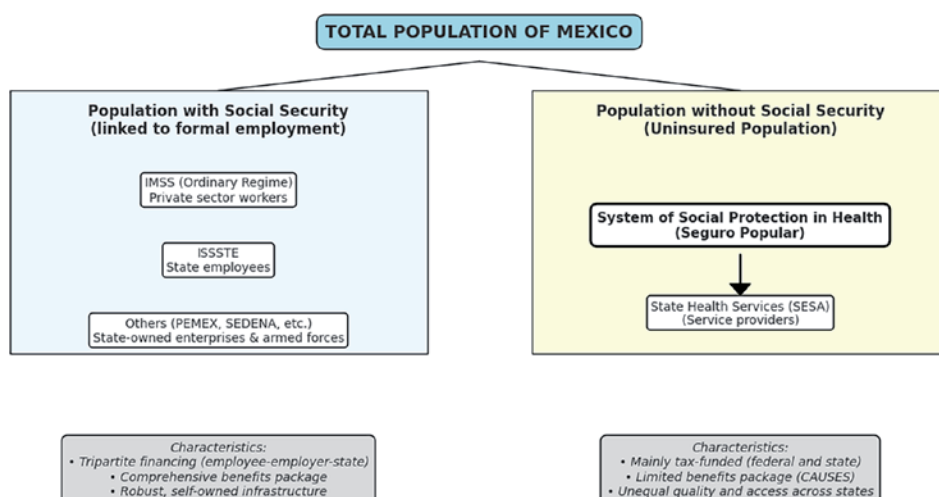


Figure 2. The organized fragmentation of the Mexican health system (2018). The diagram shows the fragmented structure of the Mexican health system before the 2018 reform. The system was divided into two main pillars defined by employment status: a robust social security subsystem for formal workers and a subsystem for the uninsured, managed through Seguro Popular and provided by the heterogeneous State Health Services. Source: Own elaboration.

landscape, and in the context of the consolidation of a market-oriented economic model, Mexico undertook a second wave of health reforms starting in the 1990s. These did not seek to reverse administrative decentralization but rather to manage it through innovative financial and conceptual engineering. The guiding principle, influenced by reform trends from international organizations, was the “separation of functions” and “structured pluralism” [3]. The idea was that the state should strengthen its stewardship role, but the financing and provision of services should be reconfigured to foster efficiency and, according to its critics, build a health market with a clear market-oriented approach [4]. This was the breeding ground for the creation of the System of Social Protection in Health (SPSS), whose operational arm, *Seguro Popular* (SP), would become the country’s most emblematic health policy for 15 years.

3.1 The cornerstone: The system of social protection in health (*Seguro popular*)

The most momentous reform of the period materialized in 2004 with a profound amendment to the General Health Law that created the SPSS. Its diagnosis was clear: the problem of the uninsured was not just a lack of infrastructure but the absence of a financial mechanism to protect families from the risk of impoverishment due to illness, as out-of-pocket spending accounted for 58% of total health expenditure in 2003 [5]. The policy was supported by strong political lobbying with state governors, who were promised substantial new financial resources for their underfunded State Health Services [4].

The design of *Seguro Popular* was fundamentally financial. Its goal was not to build a new system of hospitals but to create public insurance for the more than 50 million Mexicans without access to the IMSS or ISSSTE. Its architecture was based on three key components:

- **Per capita financing:** A financing system was established based on a “social capitalization.” For each person enrolled in a state, the federation transferred a predictable amount of money annually. This fund was composed of contributions from the federal government, state governments, and a progressive family fee, from which the lowest income deciles were exempt [6].
- **Defined benefits package (CAUSES):** Enrollment did not guarantee total coverage. The insurance provided entitlement to an explicit package, the Universal Catalog of Health Services (CAUSES). Critically, the catalog was based on “interventions” rather than the comprehensive treatment of “illnesses,” which in practice fragmented the care process and left entire segments of a disease’s care pathway uncovered. Its scope was far inferior to that of social security; one estimate from the era suggests that the SP covered barely 11% of the conditions covered by the IMSS [4].
- **Protection against catastrophic expenditures (FPGC):** To mitigate the limitations of CAUSES, the Fund for Protection against Catastrophic Expenditures (FPGC) was created, covering a limited number of high-cost illnesses.

The model was not static. During the administration of Felipe Calderón (2006–2012), the scheme was maintained with the goal of achieving “universal coverage,” adding programs like the Medical Insurance for a New Generation and changing the financing from a per-family to a per-person calculation [6].

3.2 Balance sheet of a paradigm: Achievements and shortcomings of *Seguro popular*

Evaluating the impact of *Seguro Popular* requires a balanced analysis. A systematic review of 26 studies with rigorous methodologies found mixed evidence, with positive effects in about half of the outcomes evaluated and null effects in the rest [5].

- **Main successes:** The most undeniable achievement was a massive expansion of nominal coverage. By 2018, the figure reached 53.5 million affiliates, a fundamental step toward universal coverage [5, 7]. The second major success, linked to its primary objective, was financial protection. The review by Colchero et al. [5] found that of 65 outcomes on financial protection analyzed, 55% showed positive and statistically significant effects.
- **Ambiguous results and structural failures:** Despite its achievements, the model had profound shortcomings that motivated its dismantling.
- **Deficient effective access and quality:** Nominal coverage did not translate into effective, high-quality access. The same systematic review found positive effects in only 40% of service utilization outcomes and a meager 21% of treatment outcomes [5].
- **Underfunding and failed governance:** Critical analyses pointed out that the per capita amount was insufficient to cover the real cost of the benefits package and that transfers to the states were less than legally stipulated. This was

compounded by opacity in the management of funds by the states, which led to pockets of corruption [4, 6].

- Persistence of out-of-pocket spending: Despite the reduction in catastrophic spending, total out-of-pocket expenditure remained one of the highest in the OECD, close to 45% of total health spending, forcing families to continue paying for uncovered drugs and services [6, 8].
- Discrepancies in enrollment figures: Several analyses found significant discrepancies between official enrollment figures and those reported by national surveys, suggesting that the rolls were inflated for political and economic incentives [4, 6].

4. Conclusion: The ambivalent legacy of a monumental reform

In conclusion, *Seguro Popular* cannot be judged as a resounding success or failure but as a monumental reform with a profoundly ambivalent legacy. Its most significant contribution was a historic conceptual shift: moving from a model of public assistance for the poor, based on state charity, to a paradigm of public insurance based on an explicit right, at least on paper. By enrolling over 50 million people, the SP granted a form of financial “health citizenship” to a historically ignored portion of the population, an undeniable advance on the long road to universal coverage. Robust econometric evidence confirms that its main promise, financial protection, was partially fulfilled, with a documented reduction in catastrophic expenditures.

However, the “original sin” of *Seguro Popular* was its design as a financial mechanism superimposed on a chronically weak, fragmented, and underfunded service delivery system. The reform gave the population an insurance card but did not simultaneously and sufficiently build the hospitals, clinics, and health centers, nor hire the necessary staff to meet the new demand it was generating. This fundamental disconnect between financial insurance (demand) and the actual capacity for care (supply) is the primary cause of its mixed results in service utilization and its poor effects on improving treatments [5].

Furthermore, the model deepened governance problems by relying on decentralization, which created perverse incentives. The reliance on 32 heterogeneous state systems for service provision, without sufficiently robust oversight and accountability mechanisms, resulted in notorious opacity in the use of resources and high-profile cases of corruption that undermined its legitimacy. The financing, although greater than in the past, proved to be structurally insufficient and plagued by irregularities.

Finally, the most enduring legacy of *Seguro Popular* was perhaps political and social. The gap between the promise of universal, quality health insurance and the daily experience of citizens—marked by persistent out-of-pocket spending, drug shortages, and deficient care—generated deep and widespread dissatisfaction. This perception of an unfulfilled promise eroded public trust in neoliberal-style health reforms and created fertile ground for the emergence of a discourse of total rupture. Thus, the very limitations and shortcomings of *Seguro Popular* became the political justification for its eventual dismantling and for the beginning of a new and controversial chapter in the quest for universalization in Mexico [9].

5. The 4 T model: Rupture or continuity?

The arrival of the Fourth Transformation (4 T) government in December 2018 marked a turning point in Mexican public policy, based on a mandate for profound change from the model of previous decades. In no sector was this promise of transformation more ambitious and radical than in health. The new government did not propose an adjustment or improvement to the existing system but a total conceptual and operational rupture with the paradigm that had governed care for the uninsured population since 2004. This section analyzes the nature of that rupture, its mechanisms, and its consequences, evaluating whether a fundamental transformation was achieved in practice or if the system's structural inertias led to an unexpected form of continuity.

5.1 Discursive and programmatic rupture: The dismantling of *Seguro popular*

The first act of the reform was the construction of a powerful narrative to delegitimize the previous model. The new government's critique of *Seguro Popular* was total and implacable, a stance that then-President-elect Andrés Manuel López Obrador (AMLO) had held since his time as head of government of Mexico City [10]. The critique was encapsulated in the polemically valuable phrase "it is neither insurance, nor is it popular" (*ni es seguro, ni es popular*), a slogan that, although massively popularized by the president, captured the spirit of previous academic analyses [11]. This diagnosis, politically amplified by the 4 T [10, 12], was articulated around five fundamental failures of the preceding system: (1) It failed to achieve universal population coverage; (2) its benefits package was limited and not universal; (3) it did not sufficiently reduce out-of-pocket spending; (4) it fostered widespread corruption; and (5) it did not improve the general well-being of the population.

This diagnosis, while having a clear political intention, did not emerge in a vacuum. It resonated with a decade of academic evidence that had already pointed out the model's deep limitations. Critical analyses defined it as "minimalist universalism," leading to an "inferiorizing inclusion" for the poorest, as it reinforced segmentation by offering a basic benefits package that, by 2016, covered barely 13.4% of the diagnoses included in the IMSS health insurance [13]. The 4 T's narrative, therefore, capitalized on an existing social and academic frustration.

This discursive rupture quickly translated into a programmatic one [14]. With a solid majority in Congress, the AMLO government proceeded to "raze" the previous reform to eliminate all traces of *Seguro Popular* from laws and government agencies, returning to a centralized health system model. At the end of 2019, the amendment to the General Health Law was approved, materializing the dismantling of the previous model as of January 1, 2020. This new vision was based on three key ethical principles [10, 14]:

- **Universality:** Understood as a right of citizenship, not enrollment. Care would be provided to anyone without social security, without needing a registration process.
- **Free services:** The promise to completely eliminate out-of-pocket spending by providing all services, medicines, and supplies free of charge at the point of care.
- **Anti-corruption:** A system that would reduce corruption by centralizing control over procurement and service delivery, diminishing private sector participation.

In sum, the new government's first act in health was a calculated demolition of the previous institutional edifice, marking a 180-degree turn from an explicit insurance model toward a vision of a universal and centralized public service.

5.2 Act one - INSABI: An analysis of the attempt at recentralization and universal free care

Officially born on January 1, 2020, the Institute of Health for Well-being (INSABI) was the first programmatic materialization of the 4 T's promise to transform the health system. Its conception represented a return to a centralized national health model, with integrated public financing and provision [10]. Its design was radically different from *Seguro Popular*: it eliminated the prior enrollment requirement and extended coverage to everyone in Mexican territory, including migrants [15].

However, its creation was more an act of demolishing the previous scaffolding than a carefully planned construction. The brief and tumultuous life cycle of INSABI illustrates a fundamental lesson of public policy: dismantling a reform is considerably easier than successfully implementing its replacement [10]. The start of INSABI's operations was marked by deep operational chaos, most notably its launch without published operating rules, which meant there were no clear guidelines for coordination with states or fund transfers.

The promise of universal free care—the idea of “everything for everyone”—collided head-on with fiscal reality. Despite the discourse of greater benefits, the transition involved a financial paradox: per capita spending for the population without social security actually decreased. This was compounded by significant budget under-expenditure and a contraction of the new Health Fund for Well-being (FONSABI), which impacted care for high-cost diseases [15, 16].

The decision to recentralize services, though chaotic, was justified as a necessary step to correct the failures of *Seguro Popular*'s decentralization, which had facilitated corruption at the state level. However, even proponents of this logic noted the “contradiction between the stated objectives and the financial effort made,” recognizing that recentralization alone would be insufficient without a substantial increase in health spending [17].

To this congenital weakness was added a catastrophic event: the COVID-19 pandemic, which erupted just 2 months after INSABI's creation. The health crisis not only put the new institute “under the microscope” [17] but also exposed and amplified all its fragilities. It acted as a systemic “stress test” that magnified the consequences of historical path dependency: fragmentation and chronic underfunding prevented a unified and effective national response, regardless of the program's name. By 2022, the consensus was that the INSABI experiment had failed, reflected in a regression of key indicators like maternal mortality. This failure forced the administration to seek a “Plan B,” decreeing the extinction of INSABI in April 2023 and transferring its functions to a preexisting structure: IMSS-Bienestar.

5.3 Act two - IMSS-Bienestar: The strategic pivot toward a centralized model

The operational collapse of INSABI forced a strategic pivot in mid-2022. Instead of building a new institution from scratch, the government chose to leverage a preexisting and recognized structure: the IMSS-Bienestar program. This branch of the Mexican Social Security Institute had been providing primary care in rural and marginalized areas since 1979. The logic was pragmatic: to leverage the administrative capacity, operational experience, and brand legitimacy of the IMSS to achieve the goal of centralization [18].

The operational model of the new Public Decentralized Organization (OPD) IMSS-Bienestar is based on the “federalization” of services, a process whereby state governments voluntarily sign agreements to transfer their entire responsibility for caring for the uninsured population to this federal program. This includes infrastructure, personnel, and financial resources. This represents the culmination of the centralizing vision aimed at counteracting the corruption and inefficiency of previous decentralization [17]. However, the voluntary nature of the process has created a new form of fragmentation, dividing the country between states integrated into the new model and opposition-governed states that have rejected it.

Herein lies a central tension of the reform. The decree creating the OPD IMSS-Bienestar adopts the experience of a historic program but has not fully inherited its original philosophy. The original program was founded on two pillars from the Declaration of Alma-Ata: medical care and community action. This second component—focused on prevention, social participation, and intercultural respect—was what distinguished the program for decades [19]. However, the new model has overwhelmingly prioritized a curative and medicalized approach, centered on treating existing diseases. The reform’s emphasis has been on hiring specialists and rehabilitating hospitals, leaving the preventive, community-based component that was the essence of the original program in the background. This trend is the culmination of a long process where the medical component has systematically “invisibilized” and “severed” the community one [19].

This sidelining of the preventive component is the result of three powerful forces converging: the dominance of the hospital-centric culture of the regular IMSS; the logic of administrative centralization, which favors standardization and tangible metrics (like surgeries) over the complexity of community-based interventions; and the short-term political imperative, which prioritizes high-visibility investments over the “silent,” long-term results of prevention.

The potential strengths of the new model lie in the IMSS’s management capacity. In theory, process standardization could reduce quality gaps between states. However, the challenges are monumental and largely inherited from INSABI’s failure. The primary challenge is conceptual: can a model that minimizes its community and preventive heritage succeed in the long term? Added to this are the challenges of financial sustainability, the complexity of integrating thousands of state workers into a federal structure, and the need to overcome deep territorial inequalities in infrastructure [15]. Ultimately, the success of IMSS-Bienestar will depend not only on overcoming financial and administrative hurdles but also on resolving the historic dilemma between a purely medicalized approach and the recovery of the preventive, community-oriented spirit that gave it its origin and meaning [19].

6. The transition period: Implementation challenges

The dismantling of *Seguro Popular* and the successive attempts to establish a new paradigm did not occur in an institutional vacuum. On the contrary, the transition driven by the 4 T has clashed head-on with the deep structural inertias of the Mexican health system. This period (2018–2024) can be analyzed as a phase of “disruptive containment,” whose objective was to actively halt and dismantle the inertia of the neoliberal model in order to then attempt to lay the foundations for a different paradigm. This is a phenomenon known in the social sciences as path dependency, which posits that past decisions create “increasing returns” mechanisms that reinforce the original path and make any change of course extraordinarily difficult [20].

The great challenge of this transition, therefore, has not been just changing the model but transforming nominal coverage into effective access, defined as the actual and timely use of services to achieve the best possible health outcomes [21].

6.1 The financial challenge and budgetary inertia

The main structural obstacle is financial. The promise of a universal and free system clashes with a history of low public health spending as a percentage of GDP [13]. The IMSS-Bienestar model inherited the contradiction that made INSABI unviable: an expansive service mandate versus a reality of fiscal austerity [17]. Path dependency manifests here in the difficulty of breaking with a decades-long inertia of budgetary containment, which would require a deep fiscal reform—so far unrealized—to be overcome. This chronic constraint severely limits the new model's capacity to hire staff, modernize infrastructure, and guarantee the supply of medicines and materials.

6.2 The governance challenge: Fragmentation, stewardship, and institutional confusion

The 4 T opted for recentralization to contain corruption and inefficiency [10]. However, the decentralizing trajectory created powerful subnational actors and interests that have resisted change. The refusal of several states to federalize their systems and join IMSS-Bienestar is a clear manifestation of path dependency, resulting in a new form of fragmentation [18].

Added to this political fragmentation is a crisis of governance and stewardship. The titanic effort to manage the administrative transfer has weakened the federal Health Secretariat's capacity to lead national health policy, leaving gaps in epidemiological surveillance and strategic planning [22]. Additionally, the choice of the "IMSS" brand has generated considerable institutional confusion. For the public, the distinction between the "ordinary" IMSS (for formal workers) and the OPD IMSS-Bienestar (for the uninsured population) is blurry at best. This ambiguity creates uncertainty about rights and access points, complicating patient navigation in an already complex system and acting as an organizational barrier to effective access, as it generates transaction costs for patients who do not know which door to knock on and erodes trust by creating the perception of two "classes" of IMSS [23].

6.3 The human resources and institutional culture challenge

The new model faces the monumental task of integrating tens of thousands of state workers with different hiring regimes, unions, and work cultures than those of the IMSS. These arrangements are "sticky institutions" that generate enormous resistance to change [20]. This is compounded by the cultural tension of expanding a historically community-action-focused model to absorb predominantly hospital-based and medicalized state systems [19].

6.4 Consequences for service delivery and effective access

The structural challenges of this turbulent transition have had direct and documented consequences for the population. Far from being anecdotal, problems of shortages, quality, and access have become defining features of this "containment" phase. Systematic reports from civil society organizations have documented the persistence of

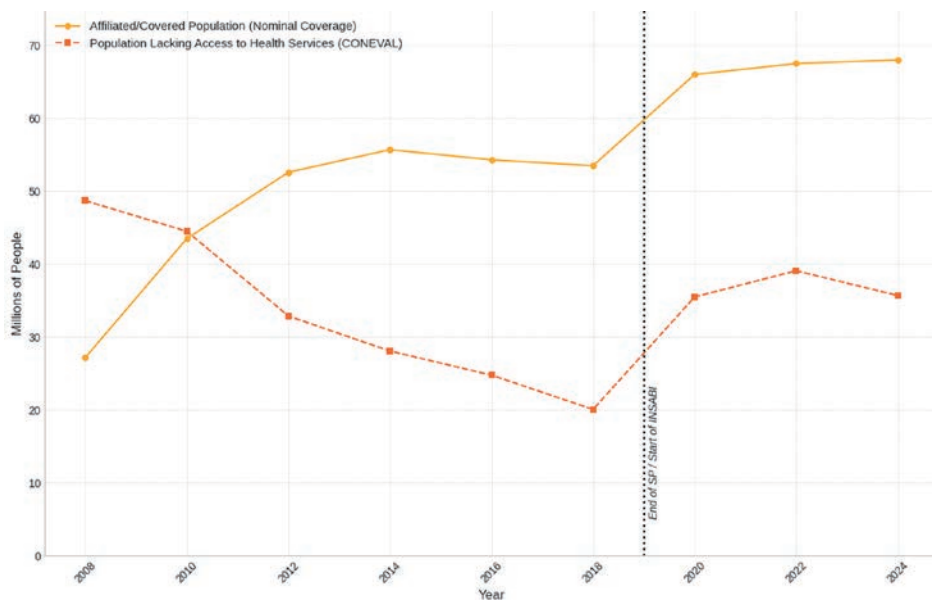


Figure 3.

The persistent gap: Nominal coverage vs. lack of access in Mexico (2008–2024). The graph illustrates the comparative evolution of the population with nominal health coverage and the population reporting a lack of access to health services. It highlights the growing gap between on-paper coverage and effective access, a structural problem that persisted and worsened during the transition of models. Source: Own elaboration based on data from the Ministry of Health and CONEVAL.

shortages of key medicines, including oncological and psychiatric treatments, linked to constant changes in centralized procurement and distribution schemes [24]. This situation has generated a widespread perception of a decline in the quality of medical care.

Perhaps the most alarming consequence has been the regression in fundamental public health indicators. The reorientation of resources and efforts toward administrative restructuring and curative care has weakened preventive programs. Recent data from the National Health and Nutrition Survey show a worrying drop in basic vaccination coverage in children under five, a setback that compromises decades of public health achievements [25].

Finally, despite the changes in models, the fundamental goal of universalization remains unmet. The most recent poverty measurement reveals that 35.7 million people still report lacking access to health services, a figure that highlights the persistence of exclusion [26]. These data confirm that changes in names and administrative schemes alone have not solved the lack of access, the structural problem that has motivated all reforms in recent decades (**Figure 3**).

7 Strategic outlook: Future scenarios and recommendations

The analysis of the 4 T's turbulent health transition reveals a system at a critical crossroads. The bet on the IMSS-Bienestar model, while pragmatic, does not in itself guarantee the consolidation of a universal, equitable, and high-quality health system. Its success or failure will depend on the strategic decisions made in the short and medium term to address the structural challenges we have documented. Based on this

analysis, this final section outlines two possible future scenarios and, based on this analysis, proposes a series of recommendations, concluding with a reflection on the goal of a single health system.

7.1 Future scenarios for the Mexican health system

- **Scenario 1: Successful consolidation toward a universal system.** In this scenario, the Mexican state manages to overcome the inertia of low public spending through a progressive fiscal reform that sustainably injects at least two additional percentage points of GDP into the health sector over the next decade. These new resources are invested strategically in the system's pillar: Primary health care (PHC) [27]. The first level of contact is strengthened, prevention and health promotion are prioritized, and the community action component is recovered, thereby containing the growth of chronic diseases. The governance of IMSS-Bienestar is consolidated, and the Health Secretariat's stewardship role is strengthened. Although the system's structural fragmentation does not disappear, progress is made toward a "basic universalism," where IMSS-Bienestar guarantees a dignified and effective floor of care.
- **Scenario 2: Chronic inertia and aggravated fragmentation.** In this pessimistic scenario, path dependency [20] proves stronger than the will for change. The budget constraint remains, and the IMSS-Bienestar model operates in a state of chronic underfunding, perpetuating drug shortages and infrastructure deterioration. The lack of resources prevents a real transformation, and the system is limited to managing existing precarity. The care model remains focused on curative and hospital-based services, unable to contain the growing burden of noncommunicable diseases. Federalization stalls, territorial inequity worsens, and the system remains trapped in a cycle of incomplete reforms that fail to guarantee effective access to health, increasing citizen frustration.

7.2 Strategic public policy recommendations

To steer the health system toward the successful consolidation scenario, the following strategic recommendations are proposed:

- **Establish a fiscal pact for health:** It is imperative to build a national consensus on the need for a fiscal reform with an explicit purpose: to create a sustainable and growing fund for health with clear multiyear goals to increase public spending to at least the OECD average [28], alongside a strong state commitment to fighting corruption in the health sector.
- **Prioritize investment in primary health care:** The heart of the transformation must be the radical strengthening of PHC. Additional resources should be directed toward modernizing health centers, dignifying the working conditions of community personnel, and implementing predictive, preventive, and participatory care models, always maintaining a balance between prevention and cure [19].
- **Redefine and strengthen system stewardship:** The Health Secretariat must transition from a crisis manager to a true strategic steward. This means strengthening its capacities for quality regulation across all subsystems, health intelligence generation, and the creation of a national framework for interinstitutional coordination.

- Create a national health technology assessment agency: To ensure financial sustainability and spending efficiency, it is crucial to create a technical and independent agency to evaluate the cost-effectiveness of new technologies before their incorporation into the public system [29].

7.3 The horizon of a single health system: A realistic goal or a long-term aspiration?

President Claudia Sheinbaum's explicit goal of consolidating a single health system by the end of her term (2024–2030), where anyone can be treated at any institution, represents the ultimate aspiration of universalism. However, our analysis of institutional path dependency compels the conclusion that achieving this goal in a single administration is extraordinarily improbable. The unification of corporate giants like IMSS and ISSSTE faces massive veto points from powerful actors such as unions [10]. Financially, upward harmonization of benefits would require a fiscal reform of a magnitude not seen in decades. An attempt at “fusion by decree” without resolving these preconditions could lead to administrative collapse.

Therefore, the most realistic and effective strategy for the next administration is not total fusion but the consolidation of the current model and the building of institutional bridges. This implies two parallel actions: first, focusing all resources on making the OPD IMSS-Bienestar function effectively [15]. Second, designing and launching a robust system of service portability and financial compensation between subsystems. Enabling an IMSS-Bienestar patient to seamlessly receive specialized care at a regular IMSS hospital with a clear payment mechanism would be, in itself, a historic success. These two steps are the only solid foundations upon which the correct, but for now utopian, horizon of a true single health system could be built in the more distant future.

7.4 Short-term recommendations: A shock plan to contain the effective access crisis

Given that structural reforms are long-term, it is ethically imperative to implement a “damage mitigation plan.” While these reforms mature, the population today faces a crisis of access manifested in waiting lists, shortages, and personnel shortages. To contain these effects of path dependency, a shock plan with high-visibility actions and tangible short-term results is imperative:

- Implement “Universalization by Agreement” to tackle waiting lists: Since IMSS-Bienestar's infrastructure will not be resolved immediately, underutilized capacity exists in the regular IMSS, ISSSTE, and even the private sector. A national high-priority universal referral system is proposed, where IMSS-Bienestar strategically purchases services (surgeries, specialty consultations) from other public and, in selected cases, private institutions [29].
- Create “Itinerant Medical Specialists” for rural coverage: To address the deficit of specialists in marginalized areas, an elite corps with short-term, high-remuneration contracts is proposed. These itinerant doctors would conduct focused surgical and consultation campaigns in rural hospitals to reduce backlogs, under a scheme of superior financial and professional incentives [27].

- Ensure supplies with a transparent “Last-Mile Logistics”: To combat shortages, a national real-time inventory monitoring platform, accessible to the public, should be implemented to exert social pressure and improve management. In parallel, hospital directors should be provided with an agile emergency fund for the local purchase of critical supplies when the federal supply chain fails.

8. General conclusions

Throughout this chapter, we have analyzed the ambitious health reform of the Fourth Transformation (2018–2024) through a fundamental question: did it constitute a paradigmatic rupture with the past, or, on the contrary, did it represent a form of continuity in the long and complex history of the Mexican health system? The evidence presented leads to a nuanced but unequivocal conclusion: the reform was a radical ideological and discursive rupture, mounted on a profound structural and operational continuity.

Our journey demonstrated that the system’s fragmentation is not a recent flaw but the product of foundational decisions of the twentieth century. The “neoliberal model,” embodied by *Seguro Popular*, was not the origin of this fragmentation but a technocratic and financial response to manage it that, despite its successes in nominal coverage, failed to guarantee effective, quality access, creating a deep citizen dissatisfaction that legitimized the promise of radical change. The 4 T executed a decisive break with that logic, dismantling the insurance model through a two-act process: the collapse of INSABI, an experiment in abrupt and poorly planned centralization, followed by the pragmatic pivot to IMSS-Bienestar. This second move, while centralizing, represented a continuity with the preexisting structures of the state, implicitly acknowledging the impossibility of building a new institution from scratch.

The structural challenges—the inertia of low public financing, the resistance of actors created by decentralization, and the persistent crisis of effective access—have proven more powerful than the political will for transformation. The promise of universality today clashes with the reality of a system that, despite changes in name, remains deeply fragmented and underfunded.

Therefore, the fundamental lesson from this administration is that political voluntarism, even with a resounding popular mandate, is insufficient to reverse decades of entrenched institutional decisions. The ideological rupture of the 4 T was real and successful in mobilizing political support, but the implementation has been a reminder that health systems are complex, resilient to change, and cannot be transformed by decree. The “transformation” has, in practice, been a redistribution of power within the same fragmented labyrinth.

Ultimately, the true universalization of the right to health in Mexico remains a pending task. The future of the system and the achievement of this longed-for objective will not depend on future institutional demolitions but on the patient and sustained building of “bridges” between subsystems, the radical strengthening of primary care, and, inescapably, the realization of a true and long-postponed fiscal pact that provides the system with the resources it has historically been denied. The search for a universal, just, and effective health system in Mexico did not end with the 4 T; it has simply entered a new and challenging chapter in its long history.

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Building Equitable Health Systems: Community Health Approaches of Governance, Participation, and Sustainability in Latin America

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Abstract

This chapter explores community health approaches in Latin America from a critical and comparative perspective, analyzing how social participation, territorial governance, and economic sustainability shape successful experiences in primary health care. Through case studies from Colombia, Mexico, and Brazil, it addresses the structural challenges these strategies face in contexts of health system fragmentation, institutional capture, and territorial inequalities. An analytical framework is proposed that integrates perspectives from health economics, distributive justice, and collaborative governance as a tool to assess the impact of community-based approaches on health equity and territorial resilience. The chapter concludes with recommendations for strengthening the integration of these approaches into national health systems and sustaining them in contexts of high social vulnerability.

Keywords: community health, territorial governance, social participation, health economics, health systems, equity, Latin America, social determinants, primary health care

1. Introduction

In Latin America, deep-rooted social, economic, and territorial inequalities have historically shaped fragmented and segmented health systems, often disconnected from local realities [1]. In this context, diverse community health approaches have emerged as innovative and necessary responses to the limitations of traditional approaches centered on curative, hospital-based, and urban-centric care [2]. Anchored in the principles of primary health care (PHC), these approaches aim to reconnect health systems with communities, promoting equitable access, culturally relevant interventions, and active citizen participation in the construction of their own well-being [3].

The relevance of these experiences lies in their ability to address the social determinants of health in an integrated and territorially grounded manner [4]. Factors such

as access to safe drinking water, food security, decent housing, and social cohesion are deeply intertwined with structural conditions of inequality [5]. Moreover, in a region marked by geographic and sociocultural heterogeneity, community health approaches offer an effective means to adapt public policies to local specificities, fostering participatory governance and accountability at the territorial level [6].

In increasingly complex scenarios, characterized by population aging, the epidemiological transition toward chronic diseases, and emerging threats such as climate change and violence, these community-based strategies have demonstrated not only technical effectiveness but also institutional resilience [7]. For this reason, understanding, systematizing, and comparing these experiences, as proposed in this chapter through the cases of Colombia, Mexico, and Brazil, is essential for advancing toward more inclusive, sustainable, and democratic health systems [8]. These lessons are valuable not only within the region but also for other parts of the world facing similar challenges [9].

The comparative approach adopted in this chapter addresses the need to analyze how different institutional, territorial, and social contexts influence the design, implementation, and sustainability of community health approaches in Latin America [10]. By focusing on three representative countries—Colombia, Mexico, and Brazil—this analysis highlights both divergent trajectories and significant convergences in how community action is articulated with formal health systems. These countries have developed emblematic experiences, ranging from the consolidation of a national strategy such as Brazil's Family Health Program, to hybrid schemes in Colombia that combine insurance-based models and decentralization, and focused rural and community care models such as IMSS-Bienestar in Mexico [11, 12].

By contrasting these cases, the chapter illustrates how factors such as political will, institutional architecture, financing mechanisms, and social organization capacity differentially affect outcomes in terms of equity, coverage, quality, and sustainability [13]. Rather than simply showcasing best practices or replicating formulas, this comparative approach aims to generate an analytical framework to understand the conditions under which community health approaches can flourish or encounter limitations [14]. It also provides an empirical and conceptual basis for strengthening cross-country learning, fostering regional cooperation, and enhancing the development of context-sensitive, culturally appropriate, and financially viable public health policies [15].

2. Theoretical and conceptual framework

This section integrates three theoretical perspectives to analyze community health approaches in primary health care: health economics, collaborative governance, and distributive justice. The combination of these perspectives allows for an evaluation not only of the effectiveness of service delivery, but also of the approaches' impact on equity and social cohesion.

2.1 Health economics

From a health economics standpoint, community-based approaches offer a valuable lens to assess the efficient, equitable, and sustainable allocation of resources, especially in settings marked by budget constraints and significant socioeconomic inequalities [16]. This perspective makes it possible to evaluate not only the costs of

delivering community-based services compared to hospital-centered models, but also the broader benefits, often not monetized, generated through prevention, health promotion, social cohesion, and the reduction of avoidable disease burdens [17]. Additionally, it provides tools to study how different financing mechanisms such as risk-adjusted capitation transfers, participatory budgeting, and performance-based incentives shape the behaviors of both institutional and community actors [18]. Political economy approaches within health economics further interrogate how decisions on resource use are made and who benefits from them, exposing tensions between technocratic approaches and those that emphasize redistribution and the right to health [19]. In the case of community health approaches, an economic analysis must consider both their social return and their capacity to generate public value, understood as collective well-being and institutional legitimacy [20].

2.2 Collaborative and territorial governance

Collaborative governance refers to the processes and institutional arrangements through which government, community, civil society, academia, and the private sector co-produce health policies and services. This approach, as articulated by scholars such as Ansell and Gash [21], underscores the importance of creating institutionalized spaces for dialog, mutual trust, and shared decision-making to address complex problems, such as healthcare delivery in historically excluded territories [22]. Territorial governance adds a crucial dimension to this framework by emphasizing the need to adapt policies to the geographic, cultural, and institutional specificities of each territory [23]. This involves recognizing both the capabilities and limitations of subnational entities in managing health care, as well as the importance of including non-health actors in collective action. In short, these approaches cannot be understood without paying attention to local power dynamics, institutional configurations, and the mediating processes that connect community efforts with state structures [24].

2.3 Distributive justice and health equity

The distributive justice perspective provides a normative foundation for evaluating whether health systems—and particularly community-based approaches—effectively help correct avoidable and unjust health inequalities [14, 19, 25]. Drawing on theorists such as Rawls, Sen, and Daniels, this approach affirms that equitable access to the social determinants of health and health services is a fundamental component of a just society [14, 19, 25]. In Latin America, where social disparities translate into profound health inequities—manifested in morbidity, mortality, and life expectancy gaps—community health approaches have the potential to function as redistributive tools [26]. They do so by territorially targeting resources, actively engaging historically marginalized populations, and prioritizing preventive and culturally appropriate interventions [27]. From this vantage point, evaluating these approaches must go beyond technical efficiency to include an assessment of their contribution to social justice—understood as the expansion of capabilities, rights, and opportunities for the most vulnerable [28]. Furthermore, this analysis should incorporate dimensions such as intersectional equity (related to gender, ethnicity, and territory) and intergenerational justice, acknowledging that current interventions shape future health outcomes [29].

2.4 Integrative synthesis of the theoretical framework

The articulation of health economics, collaborative governance, and distributive justice offers a comprehensive framework for analyzing community health approaches from structural, relational, and normative perspectives [21]. It enables a thorough assessment of the economic viability, political legitimacy, and social impact of community-based strategies. They demonstrate that success depends not only on institutional alignment but also on social ownership [19]. This theoretical integration helps move beyond simplistic dichotomies between efficiency and equity, or between participation and sustainability [30]. It affirms that community health should be understood as a public good, collectively produced at the territorial level, and grounded in principles of justice [31]. The proposed framework thus guides the analysis toward a deeper understanding of the conditions under which community-based approaches can become not only technically effective but also transformative in democratic, social, and ethical terms (Figure 1) [32].

The three dimensions of the integrated framework are not isolated but mutually reinforcing processes. Robust territorial governance provides institutional scaffolding that enables inclusive and transparent decision-making, which in turn creates the conditions for meaningful social participation. When communities are embedded in well-structured governance systems, they can exert sustained influence over resource allocation, policy priorities, and service delivery standards. This influence strengthens fiscal accountability, ensuring that public funds are used efficiently and equitably. Conversely, weak governance structures can limit participation to symbolic consultation, reducing the ability of communities to hold authorities accountable for financial or programmatic outcomes.

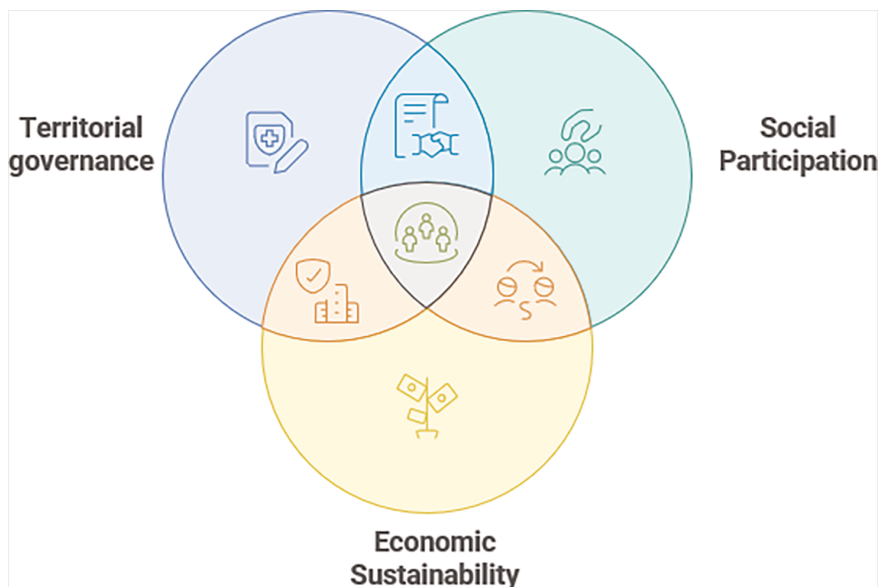


Figure 1.
Framework for analysis of community health approaches. Source: Author's own creation with the assistance of Napkin. <https://www.napkin.ai/>

3. Territorial governance

In this section, it is analyzed how the institutional structure and public administration in each country influence the implementation of community health approaches. It explores the institutional arrangements that facilitate or hinder the territorial coordination of health initiatives, considering the relationship between levels of government and local health management capacity.

3.1 The importance of local health governance

Local governance is a cornerstone in the implementation and sustainability of community health approaches, as territorial entities—such as municipalities, districts, and indigenous or rural communities—engage most directly with the population, identify their needs, and organize institutional responses [33]. Strong territorial governance enables the adaptation of national policies to local realities, ensures the cultural relevance of interventions, and promotes intersectoral coordination to address the social determinants of health [23, 32, 34].

In this context, key success factors for community-based strategies include local institutional capacity, political stability, organized citizen participation, and adequate funding [6, 35]. However, decentralization can also lead to inter-territorial disparities if not accompanied by mechanisms for fiscal redistribution and capacity building [36]. Therefore, local health governance should not be viewed as a mere transfer of responsibilities but rather as a complex process of shared accountability between different levels of government and community actors [24, 37].

3.2 Collaborative governance mechanisms

The operationalization of territorial and community governance requires concrete mechanisms that foster participation, coordination, and accountability [6]. Within this framework, health councils, community committees, intersectoral roundtables, and participatory platforms become key instruments for informed and pluralistic decision-making. When well-designed and supported institutionally, these spaces can generate legitimate health agendas, prioritize investments based on local needs, and exercise social oversight of public resources [4, 38].

Their effectiveness, however, depends on multiple factors: the representativeness and legitimacy of participating actors, the availability of accessible and reliable information, the presence of clear operational rules, and the political will of authorities to share real decision-making power with the community [24, 39]. In many cases, these mechanisms also serve as sites for civic education and as intermediaries between technical and popular knowledge, contributing to the democratization of health governance [40, 41].

Latin American experiences demonstrate that when collaborative arrangements are institutionalized and adequately resourced, they can become strategic pillars of more inclusive, resilient, and efficient health systems [27, 32].

3.3 Case studies: Territorial approaches by country

3.3.1 Colombia

3.3.1.1 System structure and territorial approach

Colombia operates a nationally regulated, mixed public-private health insurance system [42]. However, the provision of primary care services is largely decentralized, with municipalities and departments responsible for service delivery [43]. Following the decentralization process, municipalities assumed management of primary care through State Social Enterprises (Empresas Sociales del Estado, ESEs) [44]. The Colombian case illustrates efforts to implement integrated care models in dispersed rural areas, such as the Riosucio model in Chocó or various community health programs across the Pacific region's rural zones [45, 46]. Law Decree 893 of 2017 established that the National Sectoral Plans, including the National Rural Health Plan, must prioritize their implementation in the territories that make up the Territorial Focus Development Programs—PDET. Nevertheless, stark territorial disparities persist, with poorer departments showing significantly lagging health indicators compared to major urban centers [47].

3.3.1.2 Indigenous and community governance

A distinctive feature of Colombia's approach is the inclusion of Indigenous and Afro-descendant communities in territorial health planning, underpinned by legal frameworks that guarantee ethnic participation [48]. One notable example is the experience of Indigenous Councils (Cabildos) and autonomous health management within Indigenous territories [49]. The Association of Indigenous Councils of Northern Cauca (ACIN), for instance, manages intercultural health services [50]. The Association of Indigenous Councils of Northern Cauca (ACIN), for instance, manages intercultural health services [51]. This represents a form of territorial governance in which the community defines its health priorities according to its own worldview, while maintaining coordination with state institutions [52].

3.3.2 Mexico

3.3.2.1 Segmented health system and local responses

Historically, Mexico has maintained a segmented health system, with insured populations served by institutions such as IMSS and ISSSTE, while the uninsured depend on services provided by the Ministry of Health [53]. Community health programs have mainly emerged to serve rural and marginalized populations excluded from the formal system. IMSS-Bienestar (formerly IMSS-COPLAMAR and IMSS-Oportunidades) is a flagship community health model. It is state financed but locally implemented, deploying rural clinics staffed by teams that reside in the communities. These teams are supported by local health committees involved in health promotion and disease prevention [54]. Territorial governance in this context is evident in the adaptation of interventions to local conditions (e.g., indigenous customs and traditions) and coordination with municipal authorities, who often provide infrastructure or support staff [55].

3.3.2.2 Municipal health bodies

Mexico has made progress in establishing municipal health bodies (e.g., Municipal Health Councils in certain areas), although their functioning is uneven. Initiatives such as “Healthy Environments and Communities” encourage municipalities to conduct participatory local health assessments and develop intersectoral action plans [56]. A significant challenge is the lack of clear legal authority for local governments in health, as constitutional responsibility lies with the federal and state levels. This often limits territorial decision-making capacity [36].

3.3.2.3 Innovative local cases

Mexico City stands out for its extensive primary care system, decentralized at the borough level and combining public clinics with citizen committees that help identify neighborhood health needs [57].

3.3.3 Brazil

3.3.3.1 The SUS and municipalization

Brazil demonstrates robust territorial health governance through its Unified Health System (Sistema Único de Saúde, SUS). The management of PHC falls under the purview of more than 5000 municipalities, with federal and state co-financing [58].

The Family Health Strategy (Estratégia Saúde da Família, ESF) deploys Family Health Teams, including community health agents (Agentes Comunitários de Saúde, ACS), to work directly in local neighborhoods and integrate with municipal health infrastructure [59]. Brazilian regulations mandate the development of Municipal Health Plans and the operation of Municipal Health Councils, ensuring community participation in local governance [60].

This institutionalization has facilitated the expansion of primary care coverage. However, outcomes vary depending on local management capacity. Municipalities with stronger governance have achieved higher ESF coverage and improved indicators—such as reductions in infant mortality—compared to more under-resourced areas [61]. Recent challenges, such as attempts to reduce the role of ACS or budget cuts during economic crises, have strained these achievements [62].

3.3.3.2 Regional care networks

At the meso level, Brazil has developed Health Care Networks (Redes de Atenção à Saúde, RAS) to integrate services across territories. These include maternal-child care networks and chronic disease management networks, coordinating primary care with specialty services [63].

Such networks require intermunicipal governance and horizontal cooperation between neighboring municipalities, a challenge given institutional heterogeneity, which can create territorial inequities [64].

4. Social participation and community empowerment

As described in Section 2.2, collaborative governance provides the institutional framework for social participation. This section focuses on how communities mobilize

within those frameworks and beyond them, to shape health policies and outcomes. The analysis examines the mechanisms for social participation in health present in the three countries and how these practices promote empowerment, foster community ownership of health, demand government accountability, and advocate for the right to health.

4.1 Role of social participation in health

Social participation was declared a fundamental component of Primary Health Care (PHC) in the Declaration of Alma-Ata in 1978 [65]. While there are several definitions, in general terms, social participation in health refers to the involvement of the population in decisions that affect their health [66]. This implies the inclusion of communities in the formulation, implementation, evaluation, and decision-making on health policy. In this context, participation is both a means to improve health outcomes and an end itself, reflecting democratic values and citizen rights.

In Latin America, social participation has undergone significant transformation, particularly at the territorial level, where decentralization reforms and community mobilizations have created new opportunities. Participation has evolved from being viewed as an instrumental means (e.g., mobilizing volunteers for campaigns) to being considered a pillar of health governance. Today, it is widely accepted that social participation improves not only the acceptability and relevance of health interventions but also contributes to the democratic legitimacy of health policies [67].

A central dimension of social participation is empowerment, understood as a process by which individuals and communities build agency and voice to influence decisions that affect the determinants of their health and quality of life [68]. Empowerment becomes visible when communities negotiate with health authorities, prioritize resource allocation, or even co-manage programs. This approach affirms that local knowledge, lived experiences, and cultural practices are legitimate and necessary inputs in policymaking. By fostering empowerment, participation moves beyond consultation and becomes a transformative force in health systems.

4.2 Forms and mechanisms of participation

Participation in health takes place within specific territorial settings, which shape the available mechanisms and the actors involved. Participation varies in form, ranging from institutionalized mechanisms, such as legally mandated health councils and committees, to informal or grassroots initiatives. A useful framework for analyzing the depth of participation is Arnstein's ladder of citizen participation, which classifies levels from tokenism (symbolic or consultative) to full citizen power (decision-making). At the upper levels of this ladder, communities have real influence over policies and programs, and people are empowered to exercise their rights and responsibilities as citizens. In such cases, participation involves collaborative, reciprocal processes between the State and society, fostering a dialogic process that enhances agency, accountability, and self-determination [69].

4.2.1 Councils, committees, and assemblies

Countries like Brazil have institutionalized participation through legally mandated bodies such as health councils, committees, and community assemblies. These mechanisms embed participation into local governance structures, shaping how health systems respond to community demands [70].

4.2.2 Community health workers (CHW)

Community health workers or promoters are a vital link between formal healthcare systems and local populations. These workers deliver basic services, such as house-to-house vaccinations and chronic disease monitoring, while acting as cultural mediators, translating biomedical guidance into local languages and practices. They also serve as advocates for community rights, raising concerns and mobilizing local health issues [71, 72]. Below in **Box 1**, the role of CHW will be used as an example of the interrelation among the three dimensions of community health approaches.

4.2.3 Participation across the policy cycle

Participation unfolds across different stages of the policy cycle: from diagnosis and planning to implementation and evaluation. During diagnosis, communities may engage in health mapping, identify priorities, and help plan local interventions. In planning, co-design processes allow citizens to shape health plans. Implementation can include volunteer campaigns or co-managing clinics. Evaluation may involve community audits, satisfaction surveys, or social oversight committees. These mechanisms create continuous feedback between citizens and institutions, helping to improve the effectiveness, relevance, and legitimacy of health interventions [73].

4.3 Case studies: Experiences in participation by country

This section examines experiences of social participation in health in Colombia, Mexico, and Brazil. It aims to illustrate how the mechanisms of social participation in health are implemented in practice, shaped by each country's specific context and history.

4.3.1 Colombia

Colombia offers a complex landscape of social participation in health, shaped by historical inequalities, regional disparities, and the persistent impacts of armed conflict. Deep asymmetries in state capacity across departments and municipalities have resulted in unequal access to public services, limiting social mobility and exacerbating vulnerabilities in already disadvantaged territories [74].

Indigenous peoples in Colombia have endured systemic exclusion and violence. The Colombian Truth Commission has formally recognized Indigenous and peasant communities as both rights-holders and victims of the internal armed conflict [75]. In this context of historical injustice, Indigenous movements have made important advances in health equity through grassroots organizing and territorial resistance, asserting their right to health through place-based governance strategies and collective action rooted in ancestral territories.

One of the most emblematic mechanisms of Indigenous resistance is the minga, a communal practice rooted in Andean traditions of collective work (Sumak Kawsay or "good living"). Over time, the minga has evolved into a broader political and social movement used to advocate for rights to land, health, and cultural survival. Organizations such as National Indigenous Organization of Colombia (ONIC) and Regional Indigenous Council of Cauca (CRIC) have strategically employed the minga to demand structural changes, including land restitution, resource sovereignty, and intercultural health models [76]. Through sustained social mobilization, Indigenous communities have achieved significant political and legal recognition. Notably, they

have secured jurisdictional autonomy, political representation, including seats in Congress, and the creation of Indigenous political parties. As a result of this advocacy also resulted in formally establishing and implementing the Indigenous and Intercultural Health System (Sistema Indígena de Salud Propia e Intercultural, SISPI) [77].

While Indigenous communities have led the development of intercultural approaches, other forms of local participation have also emerged in urban and rural settings. For instance, in Medellín, Community Public Health Projects involve Community Action Boards in participatory budgeting and co-design of health interventions [78]. In more remote areas, local women leaders act as community health promoters, particularly in places with minimal State presence [79].

By pressure of social mobilizations in the country, the Colombian governments have also initiated efforts to strengthen integrated care models in rural territories. These initiatives, aligned with the spirit of the 2016 Peace Agreement, particularly its first point on rural reform, seek to rebuild rural territories, enhance local governance, and address historical inequities [80]. However, their success will depend on sustained investment and participatory implementation.

4.3.2 Mexico

Mexico has historically been characterized by limited citizen participation in policy development [81]. The IMSS-BIENESTAR Program has evolved both as state-led compensatory mechanism and as expression of bottom-up territorial resistance, particularly in Indigenous areas. The program has incorporated traditional midwives into its maternal health model and has developed materials in Indigenous languages to support preventive care [82].

Local Health Committees play a critical role in health promotion, needs assessment, and acting as liaisons between communities and health clinics. These committees facilitate community input into local health service delivery and help to tailor interventions to cultural and contextual realities [83].

Community health promoters provide health education and services independently of state structures. Indigenous health promoters receive training that integrates intercultural approaches, contributing to culturally sensitive health care. This role has been shown to be a good strategy for culturally appropriate and effective service delivery [84].

In urban contexts, Mexico has experience with citizen health councils in some cities (e.g., networks of healthy municipalities). A notable case is the Community Brigades strategy in Ciudad Juárez to address the violence crisis: citizens were trained to provide psychological first aid and promote services, demonstrating how participation can also impact broader social determinants such as violence [85].

4.3.3 Brazil

Brazil offers one of the most institutionalized examples of community participation in health across Latin America. The country has a long-standing tradition of social mobilization, which since the 1970s has promoted popular participation in health. As a result, the country's Unified Health System (SUS) was created in 1988, founded on the principles of universality, equity, decentralization, and social participation [70, 86].

Health councils serve as key platforms for local-level decision-making, where community representatives engage directly with authorities to shape the design and delivery of health services based on territorial needs and priorities. In Bahia, the reinforcement of social participation through deliberative spaces like health councils has been reported

fundamental to maintaining specialized public health policies [87]. However, challenges persist, such as the need for adequate financial and administrative resources to enable councils to effectively carry out their deliberative and monitoring roles.

The institutionalized participation mechanisms, supported by an active civil society, have created a strong culture of “social control” over health policies. For example, in Guarulhos, achievements in social participation include convening the First Municipal Health Conference without the presence of the Municipal Secretary of Health and the de-accreditation of a hospital that failed to meet community needs [88].

Community health workers play a pivotal role within the Family Health Strategy. These workers, typically women from the communities they serve, visit approximately 100–150 families each month, delivering health promotion messages, assessing needs, and representing the community’s voice within clinical teams. Research shows that greater activity by these workers correlates with significant improvements in hypertension control and maternal and child health outcomes [89].

Despite these advances, inclusion is uneven. Marginalized populations, such as Indigenous communities, Afro-Brazilian quilombolas, and residents of informal urban settlements, face barriers to effective participation, experiencing the effects of historical discrimination and exclusion [90]. Integrating traditional and complementary medicine as health promotion strategy shows promise in resisting the individualized and monetized “out-of-pocket” medicine model and supports the reorientation of primary health care toward a more democratic and health-promoting model for SUS [91].

5. Economic sustainability of community-based approaches

This section addresses the financial viability of community health approaches. It explores their funding sources, integration into health insurance systems, and their social return compared to conventional approaches. It also analyzes the risks these approaches face during economic crises and the strategies developed to mitigate them.

5.1 Financing and economic mechanisms

5.1.1 Mixed funding sources

Community health approaches across Colombia, Mexico, and Brazil rely on a combination of funding streams: public financing from national and local government budgets, contributions from health insurance (where applicable—such as capitation in Colombia), and in some cases, international cooperation or partnerships with NGOs.

Each country has its own financial structure. In Brazil, the Ministry of Health transfers resources to municipalities for PHC through fixed and variable components based on population and performance (PAB Fixo and PAB Variável), complemented by municipal budgets. In Mexico, IMSS-Bienestar is federally funded, with states contributing infrastructure and support. In Colombia, the capitation payment unit (UPC) for insured regimes is supposed to allocate a portion to PHC, but this has often been insufficient and is supplemented by local budgets and special projects [92].

5.1.2 Costs of community-based care

Evidence shows that per capita costs of community programs are often lower than those of hospital-centric models, while delivering significant benefits. In Brazil, for

instance, the ESF has demonstrated financial sustainability and savings by reducing avoidable hospitalizations. In Mexico, the cost per user in IMSS-Bienestar is lower than that in regular urban IMSS systems, though with a more limited range of services. In Colombia, pilot experiences in family and community health showed that modest preventive investments could significantly reduce costly emergency care. These findings support the long-term efficiency of community-based primary care, especially in addressing the growing burden of chronic disease and population aging [59].

5.1.3 Economic evaluation and externalities

Cost-effectiveness analyses—such as those measuring the use of community agents in managing hypertension and diabetes—have shown improved treatment adherence at low cost per quality-adjusted life year (QALY) gained. Beyond direct health benefits, broader externalities are also significant: local employment (as promoters are usually community members), reduced out-of-pocket health spending for families, and even cross-sectoral impacts (e.g., healthier, more cohesive communities attract investment and enhance productivity). These wide-ranging benefits reinforce the social and economic sustainability of community-based approaches [93].

5.1.4 Financial risks and volatility

Despite their advantages, community health approaches face real risks in fiscally constrained environments. Economic crises may lead to cuts in PHC budgets, as occurred in Brazil in the mid-2010s when austerity policies (e.g., the Spending Ceiling Amendment, PEC do Teto de Gastos) restricted health expenditure growth, threatening ESF expansion. In Mexico, the dismantling of Seguro Popular and the transition to INSABI introduced uncertainty in the funding of community health programs until IMSS-Bienestar took over certain functions. Colombia has struggled to finance PHC in rural areas, relying heavily on national transfers that often fall short of actual costs. Ensuring the financial sustainability of these approaches requires protective mechanisms, such as minimum mandatory spending allocations for PHC and contingency plans during economic downturns [94].

5.2 Integration into health systems

5.2.1 Articulation with universal coverage systems

A key question is whether community approaches operate as parallel programs or are fully integrated into national health systems. Long-term sustainability generally demands formal incorporation. Brazil succeeded in institutionalizing the ESF as the official entry point into SUS. In Colombia, efforts are underway to strengthen PHC within the insurance framework, including pilots for risk-adjusted capitation for PHC and the formation of Integrated Health Service Networks (RISS) that include community care as a first level. In Mexico, IMSS-Bienestar long functioned separately from Seguro Popular but is now being positioned as the cornerstone of the new public system for the uninsured [95].

5.2.2 Scaling up successful pilots

Many community initiatives begin as pilot or targeted programs. The challenge lies in scaling them up without compromising quality or local relevance. In Colombia, for

example, pilot projects led by some insurers (EPS) in rural municipalities showed promising results in prevention but faced barriers to expansion due to initial costs and a lack of regulatory mandate.

In Mexico, some states replicated the community health house strategy inspired by IMSS-Bienestar, but political will varied, limiting broader coverage. Facilitators of scale-up include legal backing, secured funding, and local evidence that convinces decision-makers. Barriers include resistance from vested interests and budget constraints [96].

5.2.3 Administrative sustainability

Beyond funding, administrative capacity is critical to implementing community approaches effectively. This includes information systems to track community-based activities, performance metrics tailored to PHC (rather than hospital benchmarks), and simplified procedures for supporting grassroots initiatives (e.g., enabling ministries to contract small NGOs or local action boards). Sustainability requires embedding community-based care into the core of health system planning—not as an optional add-on but as a fundamental component [97].

6. Discussion

Cross-Dimensional actors: Community Health Workers

Community health workers (CHWs) embody the intersection of territorial governance, social participation, and economic sustainability in practice. Operating at the micro-level or community scale, CHWs are key agents in the territorialization of health services, ensuring that services are rooted in local realities and responsive to diverse cultural, geographic, and epidemiological contexts. As trusted community members, they function as liaisons between the population and the formal health system, facilitating participation by amplifying local voices, translating biomedical guidance into culturally relevant practices, and advocating for the health needs of underserved territories. At the same time, CHWs represent a cost-effective investment in primary health care: they deliver essential services at relatively low cost, reduce the burden on higher-level facilities, and contribute to improved health outcomes in areas where professional shortages persist. In this way, CHWs reveal the operational integration of decentralized governance, community empowerment, and efficient resource allocation, making them central to the construction of equitable and resilient health systems.

Box 1.

The role of community health workers (CHW) across all dimensions.

The comparative analysis of community health approaches in Colombia, Mexico, and Brazil reveals both the transformative potential and the persistent limitations of territorialized approaches to primary health care.

A key contribution lies in their ability to bridge structural inequities by grounding health systems in community realities, integrating social determinants of health, and fostering participatory governance. The evidence reviewed demonstrates that strong territorial governance, when coupled with meaningful citizen engagement, enhances accountability, responsiveness, and cultural appropriateness of services. Moreover, economic evaluations confirm that community-based primary care is not only cost-effective but also generates wider social returns, including local employment, reduced out-of-pocket expenditures, and strengthened social cohesion.

At the same time, significant challenges persist. The sustainability of these approaches remains vulnerable to fiscal volatility, political discontinuity, and uneven local capacities. While Brazil's institutionalization of the Family Health Strategy

illustrates the benefits of embedding community health into the national system, experiences in Colombia and Mexico underscore the fragility of initiatives that depend heavily on pilot projects, donor support, or political goodwill. Furthermore, the risk of symbolic or tokenistic participation, as well as power asymmetries among state institutions, representatives, and marginalized populations, highlight the need to deepen democratic practices within health governance.

From a theoretical perspective, the articulation of health economics, collaborative governance, and distributive justice underscores that community health approaches cannot be reduced to technical interventions. Rather, they represent normative projects aimed at expanding rights, redistributing opportunities, and strengthening social resilience. Their value lies in demonstrating that efficiency and equity are not competing objectives but mutually reinforcing dimensions when health is understood as a public good.

Ultimately, the Latin American experience contributes valuable lessons to the global debate on how to build equitable and resilient health systems. These approaches show that universal health coverage is not achievable through financial mechanisms alone, but requires active community participation, recognition of territorial diversity, and sustainable investment in primary health care. The challenge ahead is to consolidate these strategies within national frameworks, protect them from political and economic shocks, and foster cross-country learning to scale innovations without undermining local specificity.

7. Conclusions and recommendations

Community health approaches to primary health care in Latin America demonstrate that health equity is most effectively advanced when services are rooted in territorial realities, co-produced with communities, and supported by stable financing. Experiences in Colombia, Mexico, and Brazil reveal that despite different institutional paths, three elements consistently underpin success: inclusive governance, meaningful social participation, and economic sustainability. These approaches show that primary health care can generate efficiency, resilience, and social cohesion, while addressing long-standing inequalities.

In practical terms, governments should: (1) institutionalize participatory mechanisms through legal and financial safeguards; (2) guarantee predictable funding for primary care, even during austerity; (3) strengthen local management capacity and accountability; and (4) promote cross-country learning to scale innovations while respecting territorial diversity.

These approaches embody principles of distributive justice, showing that efficiency and equity can be mutually reinforced. By institutionalizing and scaling them, Latin American countries can transform fragmented systems into more inclusive and democratic structures of care.

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Conflict of interest

The authors declare no conflict of interest.

Nomenclature

ACS	<i>Agentes Comunitários de Saúde</i> (Community Health Agents) Name of community health workers in Brazil.
CHW	Community Health Worker—Local health agents who deliver services, promote health, and link communities with the formal health system.
ESE	<i>Empresa Social del Estado</i> —State Social Enterprises in Colombia managing public health facilities at the local level.
ESF	<i>Estratégia Saúde da Família</i> (Family Health Strategy)—Brazil's main PHC program deploying multidisciplinary teams in communities.
IMSS	<i>Instituto Mexicano del Seguro Social</i> —Mexican Social Security Institute, a major public healthcare provider.
IMSS-Bienestar	Community health program in Mexico targeting uninsured and rural populations, formerly IMSS-COPLAMAR and IMSS-Oportunidades.
ISSSTE	<i>Instituto de Seguridad y Servicios Sociales de los Trabajadores del Estado</i> —Mexican public health system for state employees.
Minga	Andean Indigenous tradition of collective work, adapted as a political and social mobilization tool in Colombia.
PDET	<i>Programas de Desarrollo con Enfoque Territorial</i> —Territorial Focused Development Programs in Colombia, prioritizing rural and post-conflict zones.
PHC	Primary Health Care—An approach to health system organization prioritizing prevention, health promotion, and community-based care.
QALY	Quality-Adjusted Life Year—Measure combining length and quality of life used in health economic evaluations.
RAS	<i>Redes de Atención a la Salud</i> —Healthcare Networks in Brazil integrating services across territories.
RISS	<i>Redes Integradas de Servicios de Salud</i> —Integrated Health Service Networks in Colombia.
SISPI	<i>Sistema Indígena de Salud Propia e Intercultural</i> —Colombia's Indigenous and Intercultural Health System.
SUS	<i>Sistema Único de Saúde</i> —Brazil's Unified Health System, based on universality, equity, and decentralization.
UPC	<i>Unidad de Pago por Capitación</i> —Capitation payment unit used in Colombia's health insurance to finance services.

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Chapter 3

Leaving No One behind: An Attempt to Improve Health Care Equity

Mahmoud Radwan

Abstract

This chapter explores the intersection of the Sustainable Development Goals (SDGs), with a particular focus on the pledge to Leave No One behind (LNOB), within the broader context of global health. It emphasizes the interconnectedness and interdependence of SDG3—health and well-being—and other SDGs such as education, inequality, and economic development. The discussion highlights the fundamental human right to health, the social determinants of health, and the impact of socioeconomic and political factors on health outcomes worldwide. The chapter reviews the frameworks and indicators used to measure progress toward universal health coverage and reducing health disparities, underscoring the importance of data-driven approaches and accountability. It also examines the role of global organizations, challenges in achieving equitable health access, and the critical need for comprehensive policies addressing social injustices and structural inequalities. The chapter advocates for integrated, multi-sectoral strategies to realize the SDGs and ensure health equity for all populations. The chapter will discuss the key role of global organizations in achieving this pledge, identifying the main obstacles hindering them from being more effective.

Keywords: Sustainable Development Goals (SGSs), Leave No One behind (LNOB) pledge, SDG-3, social determinants of health (SDOH), healthcare equity, 2030 agenda, universal health coverage (UHC)

1. Introduction

“If we cannot all swim together, we will sink. There is no plan B because there is no planet B” [1]. This quote is from Ban-Ki Moon, Secretary General of the United Nations. Sustainable Development Goals (SDGs) that constitute the 2030 agenda for Sustainable Development form a set of 17 interlinked global goals developed to provide a blueprint for peace and prosperity (UN Department of Economic and Social Affairs, 2021) [2]. The United Nations (UN) adopted 2030 agenda in 2015 consisting of 17 Sustainable Development Goals (SDGs) including 169 targets based on the Millennium Development Goals. It aims to promote the sustainable development by addressing economic, social, and environmental areas (UN General Assembly,

2015) [3]. SGDs, including goals like No poverty, Zero Hunger, Good health and well-being, quality education, gender equality, reduced inequalities, climate action, and partnership for the goals, are highly interdependent which means that actions in one area have significant impacts on the other areas and working on them must be done simultaneously [2]. UN adopted three universal values or guiding principles that are adopting human-based approach, LNOB and enhancing gender equality, and women's empowerment [4]. United Nations Sustainable Development Group (UNSPG) explained the pledge to LNOB as an indisputable commitment of all countries to eradicate poverty and discrimination and reduce inequalities through a shared framework of action based on equality, non-discrimination, and equality in order to move beyond the achievement of average or aggregate progress making sure of the progress in all countries and among all populations at disaggregated level which required detailed data aggregation and analysis (UNSDG, 2015) [3]. Although all the global efforts were to attain the pledge of LNOB, the available data shows that the benefits of development and the progress achieved are not equally distributed through clear examples such as the low percentage of births attended by skilled health personnel in the poorest population compared to the rich population in all the developing regions and the high percentage of undernourishment in the least developed countries [5]. The UNSDG Operational Guide for UN Country Teams established a robust framework as an operational guiding plan to achieve the LNOB pledge with five steps that are identifying those who is being left behind and the root causes responsible for this problem through gathering evidence and data analysis, determining the actions required to solve the problem, monitoring the progress achieved through a clear set of reliable measures, advancing accountability LNOB pledge, and enhancing meaningful participation [6].

This chapter will give an overview of the SDGs, focusing on the pledge to LNOB, exploring SDG3 highlighting the interrelatedness and interdependence of all SDGs which means that SDG3 targets and LNOB pledge cannot be achieved without great efforts to improve other areas such as health policy, education, equality, sanitation, fighting poverty, economic development, and food supply. The assignment will focus mainly on the target of achieving universal health coverage as a cornerstone for improving health and well-being and its strong impacts on the other targets of SDG3, especially the target aiming to reduce mortality from non-communicable diseases, studying the UNSDG operational framework to achieve the pledge of LNOB. The assignment will discuss the vital role of global organizations in achieving this pledge, identifying the main obstacles hindering them from being more effective.

2. Health as a human right

The right to health, which is the economic, social, and cultural fundamental right to a universal minimum standard of health to which all individuals are entitled, is a robust concept mentioned clearly in many international agreements like The Constitution of World Health Organization [7], The Universal Declaration of Human Rights [8], The International Convention on the Elimination of All Forms of Racial Discrimination [9], and International Covenant on Economic, Social and Cultural Rights [10]. The WHO constitution health defines health as “a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity. The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion,

political belief, economic or social condition” [7]. SDG3 aims to ensure healthy lives and promote well-being for all with 13 targets classified into nine outcome targets like fighting communicable diseases, reducing mortality from communicable diseases, and achieving 4 means for achieving universal health coverage like supporting research and development of vaccines and medications [3]. The global indicator framework that has been adopted in 2017 includes 28 indicators like mortality rate attributed to cardiovascular disease, cancer, diabetes or chronic respiratory disease, coverage of essential health services, and proportion of population with large household expenditures on health as a share of total household expenditure or income [11].

3. Social determinants of health (SDOH) and health equity

3.1 The social determinants of health (SDOH) model

According to the determinants of health model developed by Dahlgren and Whitehead in 1991, there are four layers of determinants influencing health which are the major structural environment including general socio-economic, cultural conditions which needs level 1 interventions, then the living and working conditions like housing, sanitary conditions, education, healthcare services, and work environment which need level 2 interventions, then social and community networks providing mutual support from family, friends, and the local community which needs level 3 interventions, and finally individual lifestyle factors like dietary, drinking, or smoking habits which need level 4 interventions [12]. WHO identifies the Social Determinants of Health (SDOH) as the non-medical factors influencing health outcomes including the conditions in which people grow, live, work, and age and the wider set forces and systems shaping the daily life conditions which are affected by economic, social, and political factors [13].

3.2 The social gradient of health

Although the impact of medical care on the outcome of various diseases, SDOH has more significant impacts on health gains in the population (WHO, 1998) [14]. This explains the social gradient of health caused by social injustice in which shorter life expectancy and higher prevalence of most diseases can be seen in populations further down the social ladder [15]. Several studies claim that the impact of SDOH, such as income and social protection, education, unemployment, food insecurity, exceed the impacts of healthcare and lifestyle choices and accountable for 30–55% of health outcomes estimating that the impact of sectors outside health to population health outcomes is greater than the contribution of the healthcare sector [16]. The overall relative contributions of SDOH, health attitudes, clinical care, and physical environment to health outcomes were 47, 34, 16, and 3%, respectively [17]. The impact of SDOH is clearly evident in three examples that are the influential work of the Scottish physician Thomas McKeown showing the marked fall of mortality rate in England and Wales between the middle of nineteenth century till 1960 before the availability of modern advanced medical modalities because of the improved living conditions, the wide discrepancy in mortality rate among the different social classes in the United Kingdom after the establishment of the National Healthcare System (NHS) in 1948 to provide universal access to medical care, and the great paradox of the American

healthcare system showing high health expenditures with poor health measures compared to similar developed countries spending much less on health expenditures and having better results [18].

3.3 The social determinants of health (SDOH) conceptual framework

The conceptual framework of SDOH is based on three interrelated levels that are the socioeconomic and political context like governance, cultural values, social, and public policies, then the socioeconomic position determined by education, social class, gender, and income, and finally, the intermediary determinants including behaviors, biological factors, and material conditions related to living and working conditions [19]. WHO identifies social gradient, stress, early life development, social exclusion, working conditions, unemployment, social support, addiction, food insecurity, and transport as the main SDOH (WHO, 1998) [20]. Healthy People 2030 adopt a place-based framework with five areas that are Economic Stability, Education Access and Quality, Health Care Access and Quality, Neighborhood and Built Environment, and Social and Community Context [21].

3.4 Social injustice and health inequities

Social injustice can lead to health inequities due to various material and psychological disadvantages, raising the risk of multiple diseases, which indicates the importance of social welfare policies designed to offer safety nets for vulnerable populations (WHO, 1998) [20]. Absolute poverty which means lacking the basic materials necessary for life and social exclusion resulting from discrimination, racism, and stigmatization are closely associated with many health and social problems like addiction, chronic illnesses, and social isolation creating a vicious circle through which such vulnerable populations are entrapped [15]. Working conditions that include work environment and ergonomics have great impacts on physical and mental health which creates an urgency to prevent any trade-offs between health and productivity (WHO, 1998) [20]. Unemployment has significant negative psychological and financial impacts on health and well-being causing higher levels of chronic illnesses and poor mental health [15]. Addiction in the form of alcohol dependence, drug abuse, and smoking acts as both a response to social breakdown to escape from stress and a crucial factor aggravating the resulting health inequities and social breakdown like violence, accidents, poisoning, and suicide [15]. Early development has important and lasting effects on health and well-being, and poor socioeconomic conditions can negatively influence this period, which highlights the importance of supporting health needs during early development particularly for the most vulnerable populations (WHO, 1998) [20]. Healthy food of good quality and adequate availability is vital to promote health and well-being because food shortage is associated with malnutrition deficiency diseases, while excess intake is associated with many non-communicable diseases like diabetes, obesity, and cardiovascular diseases, which makes the availability of healthy food an important political, economic, and social issue [15]. WHO data reveals a difference of 18 years in life expectancy between high- and low-income countries, the majority of the 15 million premature deaths because of non-communicable diseases (NCD) taking place in low- and middle-income countries, the under 5 years mortality rate is eight times higher in Africa compared to Europe as evident examples for social injustice and avoidable health inequities [22]. In all countries regardless of their income, there is a robust inverse relationship between

the social position and the health because of the unjust and avoidable health inequities that necessitate all key players and stakeholder at national, regional, and international levels to work collaboratively to improve the daily living conditions, address the unequal distribution of power, money, and resources, and measure the problem for better understanding of the impacts of actions [13]. Although SDOH are responsible for 80% of health outcomes which means that addressing them has marked positive influence on the health of the vulnerable populations, they have not been a key focus for healthcare spending for long time [14].

4. Universal health coverage (UHC) as a cornerstone for health equity

4.1 Universal health coverage (UHC) impact on health equity

Since the 58th World Health Assembly resolution in 2005, there has been a global consensus worldwide about the importance of UHC [23]. UHC means that all people irrespective of their socioeconomic conditions can get the health services they need without facing financial obstacles [24]. The world considers UHC as an urgent aspiration for global health and a key pillar in achieving the SDGs adopted by the UN [25]. Despite the importance of healthcare as a fundamental human right strongly associated with the sense of dignity and social justice and as an essential enabler for economic growth which needs healthy people, many low-income and middle-income countries (LMIC) are still unable to achieve UHC due to many barriers [26]. UHC is a cornerstone in achieving the pledge of “Leave No one behind” as crucial commitment in the SDGs [27]. The Declaration for Transforming our World states that “To promote physical and mental health and well-being, and to extend life expectancy for all, we must achieve universal health coverage and access to quality health care. No one must be left behind” [3].

4.2 The pledge of Leaving No One behind (LNOB)

UN identified the rising inequalities across the world within and among countries as an immense challenge impeding the achievement of SDGs, endangering economic and political stability and violating the fundamental human rights, which makes the pledge to LNOB a cornerstone in the 2030 agenda and the 2030 agenda as an agenda for equality [28]. LNOB as a central cross cutting priority is more evident in the SDGs if compared to the rhetoric phrasing in the Millennium Development Goals because of two reasons that are setting clear targets to be achieved by all and enforcing detailed disaggregation of and adopting clear goals that are directly concerned with those vulnerable populations [29]. Identifying who are left behind and the causes of this challenge can be achieved by assessing five key decision-making choices and opportunities of those affected people compared to the others in the community which are: (1) Discrimination facing some people due to any factor, (2) geography enforcing some sort of isolation due to lack of public services or difficult transportation, (3) governance related issues due to lack of influence or meaningful participation in the decision making processes, (4) socioeconomic status including areas like poverty, food insecurity, unemployment and access to educational or healthcare services and finally (5) shock and fragility setting high due to climate change, natural disasters, health emergencies and violence or conflicts. The structure drivers of inequality intersect and aggravate each other having cumulative, systematic impacts

which worsen the magnitude of discrimination, inequality, and social exclusion from generation to generation (UN, 2017) [11]. According to the data in 16 countries, females in rural areas who were born to poor families and belong to an ethnic minority are the most likely to be left behind (UNPD, 2018) [30]. The pledge to LNOB needs collaborative efforts to address all sources of inequalities within and across countries including inequalities of wealth and income, which has been markedly increased since 1990, other forms of inequality are related to several factors like education which cause wide disparities in power, resources, and opportunities, gender-based discrimination taking forms like unequal pay for equal work, and gender-based violence and discrimination against other population groups on the base of race, ethnicity, religion, or any factor (UN, 2017) [11]. Global SDG progress index showed that slow rate of progress in the developing countries impeding equitable achievement of the SDGs at the global level [31].

4.3 World Health Organization (WHO) reports about health burden and universal health coverage (UHC)

According to WHO statistics in 2019, non-communicable diseases (NCD) is the leading cause of death with 41 million deaths out of the 55 million global deaths representing more than 75% of non-pandemic-related deaths, 47% of mortality cases caused by NCD occurring in low- or middle-income countries, and premature mortalities occurring before the age of 70 representing 82% of premature deaths from non-communicable diseases worldwide considering that 80% of premature mortalities from cardiovascular diseases, diabetes, and stroke are preventable (WHO, 2019) [32]. NCD represents one of the four categories of indicators forming the universal health coverage index used by WHO to monitor the level and equity of coverage in different countries [33]. The world will not be able to achieve UHC by 2030 because only 2.5–3.7 billion representing one third to one half of the world population covered by essential health services with very low percentage of 12–27% of people are in low-income countries and expectations to cover 39–63% of global population by 2030 [34]. Additionally, the escalating out-of-pocket health expenses increased exponentially pushing more people to extreme poverty with an increase in people paying out-of-pocket health expenses exceeding 10% of their household budgets to 12.7 in 2015 and expectations that 1 billion will bear such high percentage of health expenses by 2020 especially with the drastic negative impacts of COVID 19 Pandemic [34].

5. How to achieve the pledge of Leaving No One Behind (LNOB)?

5.1 Global solidarity to improve health equity

Achieving SDGs of the 2030 agenda requires global solidarity particularly with the poor and disadvantaged populations, which necessitates commitment and collaborative efforts from all stakeholders including governments, civil society, the private sector, UN systems, and international organizations across different sectors [3]. Implementing the UN system shared framework for action requires institutionalizing the UN commitment to equality through the collaborative work of the different UN agencies, adopting a comprehensive set of support policies, programs and mandates to fight discrimination and inequality, sharing tool for equality, equity analysis, measurement and monitoring, and being accountable for the results within and beyond

the UN system [28]. The UN Chief Executives Board (UN CEB) adopted a framework based on three concepts which are inequality, discrimination, and equity [6]. The 2030 agenda highlighted the importance of international public finance and the critical role of the international financial institutions to complement the efforts at the country level by providing financial resources and support especially for low-income countries that have limited resources [3]. United Nations Development Program (UNDP) identified three levers of transformational change to be implemented simultaneously to achieve the pledge of LNOB, which are the “examine” lever through the analysis of disaggregated and people-driven data and information to identify who is left behind and understand the root causes of such inequities, the “empower” lever through enabling the voice and meaningful participation of all stakeholders especially the most vulnerable populations, and engaging the civil society and the “enact” lever through integrated, equity-focused SDG policies, strategies, and financing through the analysis of the policy trade-offs caused by resource constraints [30].

5.2 Role of United Nations (UN) entities

UN system through its different entities like UNICEF, WHO, and FAO has a leading role in the 2030 agenda to support all countries facilitating the ability to reach international agreements and global mandates to achieve the pledge of LNOB by addressing the socioeconomic determinants of health and structural drivers of inequalities through a balanced, evidence-based approach including areas like achieving UHC and promoting sustainable patterns of consumption and production [3]. All UN entities must work collaboratively and align their strategic plans and policies with the SDGs to strengthen their commitment to equality (UN, 2017) [11]. Due to the importance of working simultaneously on the three levers of change, UNPD can support countries to examine by strengthening national capacities to collect, analyze, and utilize disaggregated data, working with governments and civil society to improve create effective community feedback mechanisms, enabling the utilize all available evidence for better understanding and monitoring of the SDGs progress, helping countries to empower by enhancing a right based approach in inclusive programs, helping governments in reporting data and respecting human rights, improving the capabilities of the civil society representatives and supporting the political representation of vulnerable populations, and supporting countries to enact by integrating the pledge of LNOB in policies, programs, and budgeting, establishing inclusive, accountable, and effective local governance systems, and assessing the several options for financing the actions needed [30].

5.3 Sustainable development goal 3 (SDG-3): A little progress and various hardships

Although the achievement of some gains is like the reduced incidence of some communicable diseases, there is a consensus that the global efforts are still inadequate to achieve the desired change raising strong suspicions about the ability to meet the predetermined targets of SDGs by 2030 because of the sluggish and uneven progress, which was worsened by COVID 19 pandemic [35]. The pandemic has devastating impacts on SDG3 directly by straining health systems disrupting various medical services directly or indirectly through enormous negative influence on other SDGs like pushing 40–60 million into extreme poverty or depriving 370 million school children from their free school meals [36]. Although global organizations like the

General Agreement on Tariffs and Trade (GATT), World Trade Organization (WTO), and international committees like Codex Alimentarius are accountable for setting the standards for food quality and safety, the enormous business of world food trade is heavily controlled by the global market forces because of the strong interests of food industry and the insufficiency of public health representatives in such committees (WHO, 2003) [20]. Although the Framework Convention on Tobacco Control has considerable progress in the global fight against smoking, the strong commercial interests of tobacco industry impede these efforts [37].

According to the International Labor Office, 38.9% of the world population has no legal form of health coverage with the most evident gap seen in Africa mainly in the sub-Saharan countries, 44 countries across the globe have more than 80% of population without any form of coverage or affiliation to any health system, and there is a strong inverse relationship between the coverage rate and income levels with the lowest health coverage rates seen in the countries with the high levels of poverty like Africa and the highest health coverage rates found in the countries with the low levels of poverty like Western Europe [38]. The presence of 400 million people deprived from any access to one of the seven essential services for the Millennium Development Goals and the Out-of-pocket spending estimated as 35–60% in Africa and South Asia compared to 15% only in the developed countries are all clear examples for the challenges faced by low-income and middle-income countries (LMIC) to achieve UHC [25]. Africa struggles to achieve UHC while carrying 24% of the global disease burden and having only 3% of the global health workforce [39]. In most countries, the politically ingrained Health Financing Reform (HFR) is essential to achieve UHC, which explains the importance of SDGs declaration establishing a global political commitment to support HFR and UHC at the national level [40].

5.4 Commercialization of healthcare

According to The World Bank statistics, although global health expenditure is 9.95%, global health expenditure per capita is 1110 USD, out-of-pocket expenditure is 18% globally, domestic private health expenditure is 40% globally, and domestic general government health expenditure per capita is 661 USD globally, the figures are much lower in low- or middle-income countries [41]. Although the clear inverse relationship between private sector spending relative to overall health expenditure and health-adjusted life expectancy and the significant positive impact of increasing the public spending on health on health indicators confirming the realization of health as a common good instead of a market commodity, health sector reform imposed on many developing countries due to the influence of current macroeconomic policy changes and pressures from multiple international agencies and global organizations gives bigger role for the private sector and higher priority for cost-effective interventions, which consequently leads to more commercialization of healthcare impeding the development of effective primary healthcare and public health systems [13].

5.5 Roles of global organizations in achieving the pledge of Leaving No One behind (LNOB)

Global organizations have four potential roles to play which are the translating role facilitating the translation of the global agenda into national actions, the supporting role by mobilizing resources and providing several types of aids, the coordinating role through vertical and horizontal coordination to enhance policy coherence, and the

monitoring role through regular reporting to assess the progress [42]. Global organizations must face different challenges limiting their ability to reach, enforce, and implement international agreements or conventions. Firstly, there is the complexity of the political and socioeconomic context characterized by the lack of political commitment, the arising conflict of interests between among member states or other key players like civil society, and the inability to impose effective sanctions or penalties against violating countries or institutions. Secondly, financial constraints limit the capacity of global organizations to implement their ambitious plans impeding the continuity or progress of existing programs. This is why there is an immense need to develop new national and global finance mechanisms like health taxes and to increase donations and financial aid to be 0.7% of GDP [13]. Thirdly, global organizations must face the immense power of market forces. Commercialization of vital social services like education and healthcare, trade liberalization, and deregulation under inequitable global negotiations where developing countries have little bargaining power, and the irresponsible behavior of the private sector using social corporate



Figure 1.
 United Nations Sustainable Development Goals (SDGs).



Figure 2.
 Sustainable Development Goal 3: Good health and well-being.

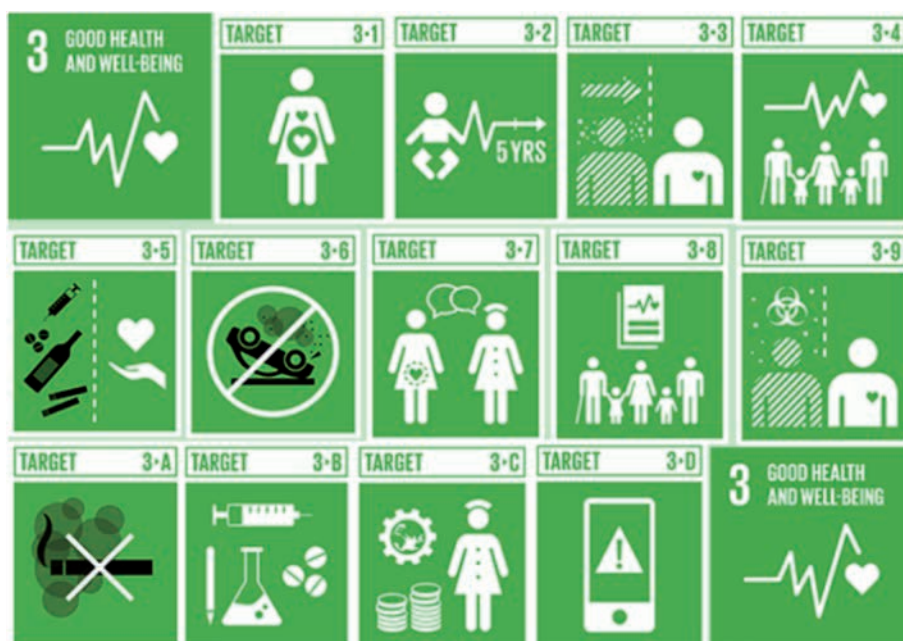


Figure 3.
The targets for Sustainable Development Goal 3.

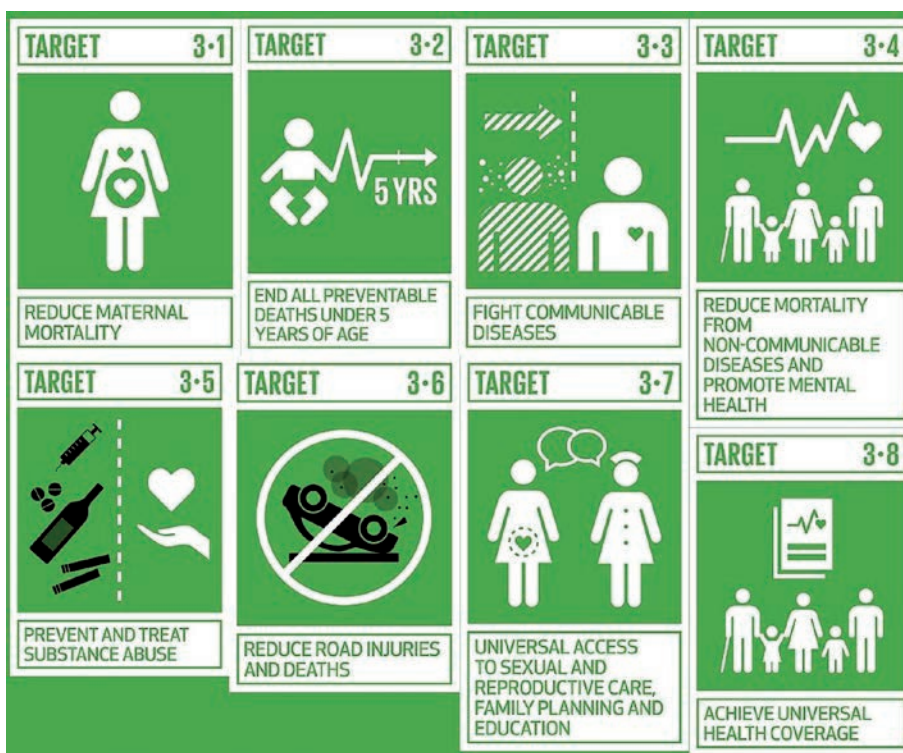


Figure 4.
The targets for Sustainable Development Goal 3.

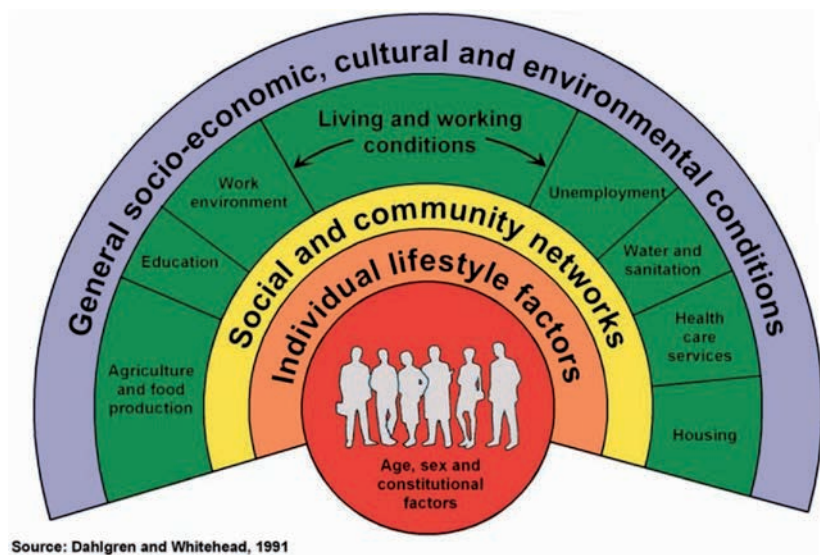


Figure 5.
Social Determinants of Health (SDOH) Dahlgren and Whitehead Model.



Figure 6.
Social Determinants of Health (SDOH)—CDC Model.



Figure 7.
Leave No One behind Logo.

responsibility concepts for cosmetic purposes are examples highlighting the importance of enhancing market responsibility [13]. Finally, the ambiguity of certain concepts like LNOB can be explained as left-behind countries, left-behind individuals, or left-behind groups within countries adding more difficulty in the translation of global agenda into action plans at global and national levels and the monitoring of achieved progress (**Figures 1–7**) [29].

6. Conclusions

The SDGs, adopted in 2015, provide an ambitious agenda in the global efforts to maintain peace, achieve prosperity, and eliminate social justice. SDG3 aims to maintain good health and well-being through 13 targets and 28 indicators to assess various areas of health including universal health coverage as a cornerstone in achieving SDGs. Determinants of health at different layers have significant impact on health and well-being, which need to be addressed through collaborative efforts from all stakeholders including global organizations, civil society, and national governments. The pledge of LNOB aims to ensure that the progress in achieving SDGs is equally distributed in by addressing the root causes of health inequities.

Global efforts to achieve SDGs are still insufficient, which increases the risk for not reaching the predetermined targets by 2030. Global organizations have potential translating, support, coordinating, and reporting roles to lead, enforce, and implement global agenda. Challenges related to the political context, financial constraints, the irresponsible market forces, and the ambiguity of certain concepts in global agreements or conventions are examples of the barriers facing global organizations.

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Conflict of interest

The author declares that there is no conflict of interest.

Acronyms and abbreviations

HFR	Health Financing Reform
LNOB	Leaving No One behind
NCD	non-communicable diseases
NHS	National Health System
SDG	Sustainable Development Goal
SDOH	Social Determinants of Health
UHC	Universal Health Coverage

UN	United Nation
UNDP	United Nations Development Program
UNSDG	United Nations Sustainable Development Group
WHO	World Health Organization

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Raising the Bar in Community Partnerships: Principles of Co-Design and Sustainability

Danielle Greene, Deborah Levine and Kamrun Nahar

Abstract

True community-partnered work is centered on mutual respect and collaboration that positions community members to shape public health outcomes. It is about actively engaging communities in the entire research and program planning process, at every level of decision-making, to ensure that their perspectives guide the work and the results. Too often, though, community members are relegated to advisory roles in which they react to predetermined plans or approve pre-written funded projects. Researchers leave when the funding lapses or the project terminates, only to ask for letters of support and participation as soon as the next grant opportunity appears. Changing these behaviors requires a deeper understanding of the commitment required to abide by the five principles of true partnership. A full realization of this framework would result in community-led and owned research. This chapter presents the evolution of community-engaged research, examines the five principles of partnership through successful practice-based examples, interrogates the institutional barriers that researchers face in implementing the framework, and offers implementation recommendations for institutions ready to raise the bar to achieve equitable partnerships in co-designing, implementing, and sustaining future public health initiatives.

Keywords: community expertise, continuous engagement, shared decision-making, transparency, trust building

1. Introduction

The primary purpose of collaboration is to bring together independent people or organizations willing to work together toward a common goal, while each maintains its autonomy [1]. It is well established, although not as well practiced, that collaboration at all levels and within all disciplines can produce better outcomes. An extensive body of public health literature on collaboration theory and methods has shown its impact on health outcomes and equity [2–4].

During the first quarter of the twenty-first century, there has been growing awareness of the critical role of community (as a whole and as individuals) [2, 5, 6].

Community engagement in public health research and intervention is grounded in the empowerment theories of Paulo Freire [7], which state that by giving people political power which they use to effect change, people gain and exert control over their lives and environment [8, 9]. Community-engaged research has developed along a continuum with increasing levels of community involvement and power-sharing by researchers (as depicted in **Figure 1**) [10].

Even with growing emphasis on collaboration and partnership, the community's role is still determined by the research team's tolerance for reduced control, the quality of existing relationships, and the requirements of the funder or institution. Collaborative approaches to community-partnered research are known by many names, each with slight variants [4, 11]. Community-Based Participatory Research (CBPR), the most commonly known, approaches developing, implementing, analyzing, and evaluating research and interventions collaboratively with the goal of maintaining the relevance and applicability of findings to the community [2]. In CBPR and many similar approaches, those initiating the research—usually members of a university or government agency—are not considered members of the community. Researchers are often outsiders who have a reputational history of conducting research on communities and then abandoning them [12]. Yet a tenet of CBPR is the sustained, meaningful involvement of the community in every aspect of the research process. CBPR is not just about gathering data. It is about actively engaging communities in the decision-making process [13–15] and ensuring that their perspectives guide the work [16]. Fulfillment of this vision would be community-led research by community members in positions

	Advising	Collaborating	Partnering	Leading
Example	Invited by researchers, based on existing relationships, meets as a group of 10-30 to hear presentations / answer questions	Community-led recruitment, makes recommendations on who/where to recruit, receive preliminary reports on findings, may provide feedback research findings and/or give context to help interpret research findings	Community defining research topic, questions, approach with researchers, developing research instruments with researchers, participating in analysis, helping to write publications / presentations (any combination or all, the more activities, the more of a partnership it is)	Community defines issues, design research, identifies academic partner to assist/fill gaps, is the funding recipient of record, directs project, can be primary decision maker or share decision making with researchers but with eye to meeting community needs
Characteristics	- Represents target population of research or intervention - Talked at - Gives feedback - No obligation for researchers to incorporate feedback - Created due to funding requirements - May or may not receive compensation for participation - Acknowledged but not credited in publications, presentations, research briefs	- Active participation in one aspect of the research - Defined parameters - Feedback is integrated into project results and conclusions - Required by funder or deliberate choice by researchers - Usually, stipends given - Acknowledged but not credited in publications, presentations, research briefs	- Shared decision-making - Active engagement in all stages of the research process - Recommendations and participation have same value as researchers - Community insight integral to process and can lead to changes in research plan - Opportunities to engage in analysis, writing, presentations - Appropriate compensation provided for community time, effort, and expertise (including lived experience) - Credited in publications, presentations, research briefs	- Authority to make decisions or share decision-making - Leads all stages of the research process - Researchers take direction from community (community can designate researchers as leaders on methodological issues) - Community insight integral to process and can lead to changes in research plan - Analysis, writing, presentations led by community - Appropriate compensation provided for research participation - Credited in publications, presentations, research briefs
Approach	Community advisory board	- Community-based participatory research - Patient/community-engaged research	Community co-design	Community-led research

Figure 1. Continuum of collaboration, partnership, and shared leadership in community-engaged research. This figure was adapted from the community-engaged research framework by NORC at the University of Chicago [10].

of leadership within all entities conducting research [13, 17]. Importantly, community engagement models are frameworks within which any methodological approach can be applied. They are not methodologies on their own [10].

Structural barriers embedded in research and institutional processes [17–19] continue to impede true joint ownership. These barriers range from health topic-specific funding streams, upon which researchers are dependent and which often determine the project's subject before the community is ever engaged, to the time-limited nature of project funding, which prevents sustainability from the outset, to the lack of credit given to academic researchers for the efforts involved in building and maintaining community relationships between projects. The lack of sustained investment in community engagement has resulted in isolated research projects and topic-specific advisory boards that are ancillary to the core of the research, reducing communities to passive sources of data and approval.

The resulting transactional relationships tend to dissolve once funding ends, and yet researchers repeatedly return to these same communities when new grants require “community input.” This approach has fostered deep mistrust and disengagement [2]. In contrast, community co-design emphasizes collaboration, transparency, and long-term partnership [20, 21]. Authentic community engagement cannot be transactional. Instead, it must be rooted in long-term commitment, mutual respect, belief in shared ownership of knowledge and outcomes, and ideally, sustainable models of funding.

This chapter will examine the underlying effort involved in building lasting community partnerships by highlighting principles of engagement, sharing lessons from the field, and offering practical examples of how community co-design can reshape the relationship between public health institutions and the people they serve. Using the concepts of shared power, accountability, mutual benefit, organizational readiness, and the ethical responsibility to return results to the community, it will demonstrate community co-design can move collaborative work beyond extractive engagement toward equitable partnerships.

2. Understanding community co-design

Community co-design is a collaborative process that centers shared power and shared purposes. It brings community members and institutional partners together from the beginning to identify problems, shape goals, select methods, and interpret results. Rather than being consulted after decisions are made, community members help define what the work should be and how it should unfold. In public health, co-design acknowledges that the individuals most directly affected by an issue possess essential knowledge about its causes and potential solutions. It reframes residents not as data sources but as architects of the interventions and systems that influence health and well-being.

In this context, community refers to any group of individuals with a shared demographic, socioeconomic, cultural, or geographic connection. This can include people living in the same neighborhood, those with similar health conditions, or groups united by a common goal or identity [8]. Collaborations may occur among academic researchers, governmental agencies, community-based organizations, health care facilities, or other stakeholder groups [11, 22]. The principles of co-design apply wherever there is a power imbalance between program designers and those who live with the outcomes.

Public health projects often begin with good intentions but fall short in practice. Communities are treated as recipients of services rather than as experts with insight to offer. Once a project concludes, relationships fade. When the next funding cycle begins, the same communities are asked again to give their time and stories. Repeated short-term engagement erodes trust and can deepen harm. Co-design offers an alternative path, one grounded in long-term collaboration, transparency, and sustained partnership.

Community co-design elevates the stories of those whose lives are shaped by public systems, highlighting the experiences of individuals who are often overlooked or underrepresented, and making it possible for them to have an active and meaningful role throughout the process, from the choice of topic to methodology and pace of research, to interpretation, analysis, and dissemination. This is achieved through a commitment to principles of true partnership.

3. Principles of true partnership

True partnership means working with communities as equal collaborators who share authority, accountability, and benefit. It is not a short-term alliance or a means to secure participation in a single project. It is a sustained relationship built on mutual respect, transparency, and the exchange of both expertise and trust. In a true partnership, each party contributes to its own strengths, complementing one another. Community members bring their lived experiences and local insights, while academic and institutional partners contribute their technical knowledge and resources. Together they make decisions, interpret findings, and plan action in ways that reflect collective ownership.

Five guiding principles support this approach: respect for lived experience, early and continuous engagement, shared power and decision-making, transparency, and long-term trust-building (Figure 2). These principles are not theoretical ideals; they are practical approaches that can be adapted to a variety of public health initiatives. Regardless of the topic or scale, they help ensure that engagement is meaningful, ethical, and sustainable.

Principle	Description
Respect for Lived Experience	Acknowledging the value of unique knowledge and experience community members bring
Early and Continuous Engagement	Community involvement should begin at the earliest stages of a project and continue throughout its lifecycle.
Shared Power and Decision-Making	Redistributing decision-making power, ensuring that community members have an equal voice in shaping policies, initiatives, and strategies that affect them
Transparency	Clear and open communication about processes, decisions, and outcomes.
Long-term Trust-Building	Not a one-time effort but an ongoing process of relationship-building

Figure 2.
Principles of successful partnership in community-engaged research.

3.1 Respect for lived experience

Respect for lived experience is central to community engagement. It recognizes the value of the unique knowledge and experiences that communities bring. Practitioners must view communities as experts in their own right, particularly in understanding the emotional, social, and psychological impacts of policies on their everyday lives may leave deep, lasting psychological scars [23]. Their lived experiences are integral to identifying the challenges they face and to developing effective and sustainable strategies. Integrating this concept into research challenges the traditional view that expertise resides solely in academic or institutional spaces. Genuine respect involves more than acknowledgement. It requires a commitment to actively listening with humility and openness, and engaging the community as equal partners in knowledge creation.

Founded in 2020, the Harlem Health Initiative (HHI) at the City University of New York Graduate School of Public Health and Health Policy (CUNY SPH) aims to improve the health and well-being of the Harlem community by supporting local community-based organizations (CBOs). HHI's [24] first project was a comprehensive process of listening to community stakeholders to develop a complete understanding of the health-related needs and the organizations filling those needs of the Harlem community. After learning which service organizations were tackling the most urgent needs of the Harlem community and what gaps the organizations had, HHI provided capacity-building support to them. By involving all parts of the Harlem community in every step of the process, HHI fostered a deeper connection to the work. This helps ensure that past, current and future projects are grounded in the community's real needs.

HHI demonstrates humility and openness by prioritizing representation as a guiding value. When HHI develops a co-designed project, every meeting begins with questions such as, "Who is missing from this conversation?" and "Whose story still needs to be told?" This practice has brought in caregivers, faith leaders, small business owners, elected officials, community stakeholders, community boards, youth, and elders. HHI's successful events reflect this intentionality with a diverse cross-section of society in attendance each time. By utilizing the community co-design framework, HHI has evolved into a community-driven infrastructure that mobilizes leadership across sectors, sustains collaboration through shared ownership, and fosters a space open to everyone who enters.

Over the past 5 years, HHI's approach has addressed Harlem's public health priorities, ensuring that the programs developed reflect the lived experiences of those most impacted by social and racial inequality. During the height of the COVID-19 pandemic, HHI monitored community needs and continued its capacity-building programs to help local CBOs respond appropriately. This included developing virtual communications and outreach on vaccinations, provider maps, data collection and report backs, and resource navigation [25]. Another HHI co-led needs assessment identified mental health challenges and unmet social needs. The resulting program, Harlem Strong, uses a community-engaged framework to integrate mental health and social services into Harlem's local infrastructure [26].

As shown by these HHI examples, community co-design can be utilized to understand community needs and develop culturally relevant and effective interventions. Community co-design can also be used to create and test theory-driven interventions to promote health and reduce disease in populations with significant health disparities [27]. Involving community members in the research process ensures

that interventions are tailored to the specific needs and contexts of the populations to be served. Employing non-traditional qualitative strategies such as photovoice and storytelling can create spaces for open dialog among community members and researchers [28, 29]. These methods empower communities to document their own experiences and actively participate in the research process, ensuring that their voices are heard and respected.

The Public Health Education Now (PHEN) project used oral history methods to examine the impact of the twindemic of COVID-19 and racial injustice uprisings on the changing landscape of public health education. Two faculty members partnered with a student team to conduct a narrative analysis of the pedagogical journey they and their colleagues took during this time [30, 31]. The project identified a need to incorporate the lived experiences of both faculty and students into the classroom to address structural barriers to learning and enhance engagement with the material. This is in accordance with considerations of reflexivity and positionality in qualitative research. Similarly, researchers must bring their whole selves into community work from the start of the relationship-building phase [32]. It is not respectful or fair to expect community partners or participants to be vulnerable when researchers are not. By sharing their intersectional identities and lived experiences to the extent relevant, especially if there are connections between identity and the motivation for the project, researchers bring humility and openness into community-engaged work.

Incorporating respect for lived experience reimagines the traditional research and policymaking roles that often exclude marginalized communities from shaping the systems and policies that affect their lives. Respecting and amplifying the voices of those with lived experience confronts these power dynamics and creates more equitable and effective public health interventions. As these examples demonstrate, respect for lived experience is not simply about listening; it is about engaging with authenticity, humility, and an openness to be transformed by the knowledge communities hold.

3.2 Early and continuous engagement

Early and continuous engagement is another critical principle, emphasizing that community involvement should begin at the earliest stages of a project and continue throughout its lifecycle. This ongoing engagement ensures that the work remains relevant and responsive to the community's evolving needs.

Collaboration must begin before any research proposal is written and should continue long after the last survey is collected [8]. Community engagement involves more than recruiting diverse participants or seeking letters of support from groups representing marginalized populations [9]. It encompasses identifying, describing, and explaining the mutual benefit of the proposed work and engaging with the ideas of the community to ensure that there is genuine reciprocity as well as understanding of, and agreement on, the benefits.

The Options Study, a community-engaged assessment to understand the under-utilization of a public hospital's¹ reduced fee program, demonstrates this principle in action [33]. Hospital administrators, CBO representatives, and researchers worked together to develop a methodology for the study - community member focus groups

¹ In the US, even public hospitals may charge for services. Several reduced fee programs are offered by these hospitals and no one is turned away due to their inability to pay.

and key informant interviews with organizational leaders. Ultimately, researchers, and community representatives co-moderated 21 focus groups in six languages in both community and hospital settings across all five boroughs. Community partners had the option of participating in data analysis but chose to have the research team present preliminary findings for discussion and feedback. After incorporating the feedback, the penultimate report was shared again with all partners [11].

By playing a role in developing each aspect of the study, the community ensured that the questions and results reflected their concerns and priorities. This approach fostered a sense of ownership and agency in determining the systems that were supposed to help their communities. When developing studies, researchers should engage community members in selecting and shaping the study's methodology. This includes adopting nontraditional approaches that may more accurately reflect how the community understands and conveys its shared history, while also allowing community members to drive the research process. In the Options Study [33], for instance, there was a specific request by a community partner to include an additional cultural group. An additional targeted focus group was added, even though, as the research team anticipated, the data collected from it was insufficient to influence the study's findings [11, 22]. In this case, early community engagement in the design phase, shared decision-making regarding methodology, and inclusive representation of all relevant groups were ultimately more critical to the project's success than the effort expended for and subsequent contribution of results from a single additional focus group.

3.3 Shared power and decision-making

Shared power and decision-making involve redistributing decision-making authority, ensuring that community members have an equal voice in shaping policies, initiatives, and strategies that affect them. Community co-design emphasizes the importance of shared decision-making at every stage of a project, from setting goals and gathering data to analyzing results and disseminating the findings [34]. Sharing power enhances the relevance and effectiveness of public health research. By integrating community perspectives, public health initiatives become more aligned with the needs of the people they serve, making them more sustainable and impactful. Ideally, project teams would include community leaders and trusted liaisons as principal investigators, giving them recognizable equivalency to the lead researchers.

Training community members not only to participate in research but to take on the role of researchers themselves builds ongoing capacity and ensures community voices influence the outcome of the work directly, reinforcing the principle of shared power. In a study of home care workers' experiences with client death and grief, researchers trained participants to conduct reciprocal peer interviewing [35, 36]. During the training, some participants began to discuss the interview topics in-depth, sharing relevant information that informed the creation of questions and later findings. It also furthered the relationship among the research team, which now included these participants, leaning into the collaborative nature of the methodology. The home care workers gained a new set of skills, including research interviewing, and helped direct the flow of the research.

Many research projects employ community advisory boards. Unfortunately, these are often seen as ancillary to the "main research" and function in a pro forma way – meeting for the sake of meeting, to check off a requirement, or approve decisions that researchers have already made. Scholars who have committed to community co-design instead use these boards to actively shape the research in real time. Members of

the advisory boards offer valuable input on everything from refining research questions to providing feedback on the study's design. The story behind research assessing the local impact of the closure of New York City's (NYC) Saint Vincent's Hospital highlights how community members can have a genuine role in the development and direction of research, making sure the work reflects their concerns and needs [37, 38].

In this study, the researchers were part of a 40-member Steering Committee composed of elected officials, residents, healthcare providers, advocates for people with various health conditions and sociodemographic characteristics, and other stakeholders. The researchers represented a neutral external partner. The Steering Committee co-designed the research questions, methodology, data collection instruments, and dissemination process. While the researchers initially recommended a more structured sampling guideline to define the study population, the steering committee advocated for a broader approach that would better represent the community. Demonstrating the principle of shared power and decision-making, the researchers accepted and implemented the community's preferred approach after clearly explaining the potential limiting effect on the results [11].

These works demonstrate that shared power is not only essential to community engagement but also crucial in achieving more effective, culturally relevant, and sustainable public health outcomes. By ensuring that communities are actively involved in decision-making, public health work becomes more aligned with the real needs and priorities of the people it serves.

3.4 Transparency

Transparency involves clear and open communication about processes, decisions, outcomes, and benefits to the community. It helps build trust by ensuring that all stakeholders have access to the same information and can hold each other accountable. In particular, communities deserve clear information about how data will be used, who benefits, and what comes next. This includes prioritizing measurable benefits for the community (e.g., policy shifts in health access or education access) over grant requirements, research publications, and/or the researchers' career progress. Often, the requirements of the funder or the institution do not align with communities' expectations and/or capability to deliver these as expected by the funders. At HHI, transparency is a core value. The HHI team informs residents about project developments, health assessments and results, as well as community engagement activities. This transparency fosters a sense of collective ownership and reinforces the community's role in the initiative's success.

The Supporting Parks and Revitalizing Communities Study (SPARCS) employs a community-engaged approach to enhance park-based health and social programming [39]. In this study, design teams are composed of community members, research staff, and professional designers. The design teams generate ideas for how to gather data/information, how the park should be used, how to encourage the community to use the park, and how to design the activities. SPARC's goal is that, once the initial program is designed, the community will be at the helm with the professional designers and researchers in support roles. The trust and transparency have led to breakthroughs in which community members identify not just what they need from the park but what others in the community will need (change in perspective). These insights help, but do not fully compensate for missing representation [Emma Tsui, PhD, SPARCS Investigator, communication via Zoom, October 3, 2025]. This can be achieved by bringing more community members into the process [see 3.1, HHI].

The more community co-design is embraced at the partnering level throughout the process, the less effort will be needed to maintain transparency. This is because it will not be a separate activity for the researchers. Rather, if the community is involved as leaders and participants at every stage, natural transparency should be inherent.

3.5 Long-term trust-building

A key concept in community-engaged work is the importance of establishing long-term, sustainable relationships with communities [12, 17]. The Engage for Equity project at the University of New Mexico, and related projects by this research team, has explored in-depth the role of trust and trust-building in community-based projects. Study results emphasize the need for best practices such as centering culture, sharing power, formal agreements, and collective decision-making [13, 17, 20, 40–43].

Trust-building is both a best practice and something that can be achieved through these other practices, making it both an input and an outcome. Creating safe spaces, listening, transparency, empathy, embracing diversity, and demonstrating authenticity are traits [17, 19] that create a “community circle of trust building” [18]. Another essential element is remembering that it is not just that the researchers need to earn the community’s trust. The researchers must trust the community and demonstrate it. Working with the same communities across multiple projects and investing in relationships that go beyond data collection leads to sustained efforts that create multifaceted relationships as researchers, collaborators, and allies [21].

HHI’s engagement begins with understanding what matters most to partners and potential collaborators, their motivations, priorities, and capacities. Seeking support for new community-engaged projects is not an act of persuasion, but rather a matter of connection. HHI staff attend community board² and health committee meetings regularly, not just when they have a project to present, host expert and community panel webinars on topics requested by partners not related to funded initiatives, and create social media content on civic engagement [24]. This practice acknowledges that relationships are reciprocal and cannot be sustained solely by need. This consistency has woven HHI into Harlem’s social fabric, positioning it as a living infrastructure that responds to and evolves with community rhythms. Meeting partners where they are means honoring their timing, resources, and commitments. Over time, this trust becomes the foundation upon which shared work can take root and sustain itself long after any single initiative concludes.

In PHEN, the faculty leaders recognized the need to build relationships based on trust, safety, and “generous listening” among the research team, composed of faculty and students. This was particularly important because the research leads were also narrators or participants in providing oral history, which meant the students were responsible for analyzing these transcripts. Over the course of the project, a moment came when the team realized “painful tensions, mistrust, and harms were impeding” their relationships and the project. They “realized that even though our research project was about students’ lived experiences amid the twindemic’s losses and challenges, we had not taken time to share our own stories and values.” It took difficult conversations, self-reflection, one-on-one conversations, and facilitator-led restorative healing

² Local advisory bodies within NYC government structure that represent neighborhood interests and address community needs. There are 59 Community Board districts citywide, each staffed by up to 50 volunteer members.

circles in which deep listening, vulnerability, celebration, and caring were modeled for the team to create a sense of trust, healing, and rebuilding. Ultimately, the team was able to move forward, with more profound knowledge and understanding of each other, their lived experiences, and their motivations [31].

Authentic community engagement is about staying the course, even after the formal conclusion of a project, to ensure that the community's voice remains integral in shaping future efforts. Partnership does not happen overnight. It grows from mutual respect, shared goals, and a willingness to shift power. It is a commitment to work differently: to build trust gradually, to listen attentively, and to co-create programs that reflect the genuine needs and strengths of the people.

4. Compensation and credit-sharing

Fair compensation and credit-sharing are key practices in building authentic community partnerships in public health. Fairly compensating community members affirms the value of their expertise and ensures that participation is bidirectional and not extractive. Equally important is the recognition of community contributions through authorship, acknowledgement, and visibility in research and practice. Together, these practices move engagement beyond transactional involvement, building the foundation for trust, accountability, and long-term collaboration.

4.1 Models for compensating community expertise

Compensating community members for their expertise is critical to ensuring equity, trust, and respect in public health research and programming. Oftentimes, communities are asked to contribute their time, knowledge, and lived experience without fair acknowledgment of the value they provide [44].

Emerging models for compensation are moving beyond token stipends, vouchers, or gift cards. Instead, the models suggest structured approaches that enhance community trust and mirror professional consulting practices, such as hourly rates aligned with local wage standards and honoraria for participation in advisory boards. This shift formally recognizes community members as collaborators and establishes operating standards that ensure timely disbursement of payment [45–47]. These models also incorporate flexible payment options beyond gift cards, such as cash, checks, or direct mobile payment, allowing community partners to choose the method that best meets their needs [45]. Budgeting for compensation from the outset helps to avoid the common problem of underpaying or underfunding contributions from community partners [48]. These models position community members as equal partners and affirm that their expertise is central rather than supplemental.

Embedding compensation practices into organizational workflows provides the opportunity to transform engagement from a one-time exchange into a sustained partnership. Institutional and administrative barriers often hinder equitable compensation practices. Challenges such as rigid fiscal policies, limited funding flexibility, lengthy approval processes, and burdensome or unclear administrative procedures can delay or restrict the payment of funds to community partners. Addressing these structural constraints requires securing buy-in from institutional leadership and continued advocacy to integrate engagement principles within institutions and across projects. Thoughtful implementation enables compensation practices to function as a dynamic system that reflects the shared values of trust and respect. Paying

community members should not be an afterthought but rather a built-in mechanism that demonstrates the value of their expertise and labor. This requires early planning during proposal and budget development stages, as well as the integration of compensation practices into project design. To ensure transparency and accountability, it is essential to establish partner expectations and clear protocols for determining compensation eligibility, pay scales, timely disbursement of funds, and flexible payment options. Equally important are ongoing dialogs to reflect upon and reassess compensation as roles and partnerships evolve over the course of a project. Having a structured yet adaptable approach allows the compensation process to remain both equitable and sustainable across projects and collaborations.

The NYC Preparedness & Recovery Institute (PRI) [49], a public-private partnership between ICAP at Columbia University and CUNY SPH, was created to strengthen NYC's ability to prepare for, respond to, and recover from major health emergencies. PRI's Community Convening and Learning Team (CCLT) developed a compensation model [50] to guide PRI's community-centered work across research, programming, and preparedness activities. The purpose of the Community Representative Compensation Plan is to establish a fair and transparent system for compensating community representatives that recognizes their time, expertise, and lived experiences while ensuring compensation is determined collaboratively and equitably. CCLT's compensation model is grounded in the core principles of community engagement embedded in PRI [51], providing operational guidance on the various forms of participation that PRI may request, a framework for implementation, and principles to uphold before, during, and after engagement. Additionally, the model incorporates compensation methods that extend beyond financial means, reflecting a more comprehensive approach to valuing collaboration. Together, these guidelines strengthen community representation, elevate innovation and leadership, and support the sustainability of PRI's partnerships.

4.2 Ethics of recognition and authorship

Beyond monetary compensation, recognition and authorship are core tenets in community co-design. Despite contributing significantly to research, programming, and evaluation, community partners may be excluded from publications, presentations, funding acknowledgments, or access to grant opportunities that often remain limited to large academic or research institutions [52]. Upholding ethical standards means ensuring that community contributions are acknowledged and recognized in tangible and visible ways, such as co-authorship on scholarly articles, inclusion in reports, and shared opportunities to present findings. Credit-sharing fosters transparency, accountability, and trust. This practice not only affirms the intellectual ownership of community members but also challenges traditional power dynamics that legitimize academic voices over lived experiences [52].

5. Recognition of community accomplishments and assets

Community health assessments comprehensively identify the assets and needs of a defined group. When conducted in tandem with community members, community health assessments provide a window into how a community perceives itself, the systems and patterns it operates within, and its assets and needs. Communities and public health practitioners/researchers should partner to utilize this information to

build capacity to improve health and equity. Health equity initiatives usually start from a deficit perspective, focusing on gaps, needs and weaknesses. Most communities are fully aware of the issues and barriers they face; in fact, they know the hows, whats, and whys better than the researchers do. A more collaborative approach is to focus on naming a community's assets and how they can be expanded upon [53, 54]. Building sustainable relationships and results may benefit from starting from a place of strength [55]. Even in the most devastated communities, existing relationships and social capital can serve as the foundation for positive action [56].

A frequent community complaint is the numerous studies examining the same factors, collecting the same data points, or, worse, ignoring the work already conducted by the community. The COVID-19 pandemic drew attention to gaps in health care delivery, public information, and access to resources in under-resourced and marginalized communities, and how, in the first stages of the response, these communities had been ignored. As the pendulum swung the other way, government agencies and researchers dedicated time and effort to documenting these service gaps and their impact, even though for the most part it resembled every other disease landscape for which structural barriers are the major contributing factor. CCLT, in partnership with HHI, took a different approach. Rather than speaking for these communities, CCLT and HHI conducted an Environmental Scan [57] to document the research activities undertaken by CBOs, faith-based organizations (FBOs), health departments, and research/academic institutions in NYC and to describe the resources being accessed to meet community needs since the start of the COVID-19 pandemic. Findings showed an active research community already in place with resulting programs and activities based on the proven understanding of the impact of the pandemic and bridging connections between health services and human/social services. The scan revealed that CBOs have consistently provided data on community needs, the types of services they offer to communities, and the barriers or challenges they encounter during the provision of services and resources. Even with inadequate funding and a lack of systemic support, CBOs continued to fill gaps where city services were insufficient. The report provided a strength-based portrayal of the NYC communities, highlighting the accomplishments of the community in data gathering, analysis, and service provision.

6. Sustaining community-engaged work

Analyses of sustainability in public health tend to focus on results or program continuation [58]. The health outcomes can take years to observe and measure. If the results are positive, it is natural to want to continue the program. Regardless of program length or evaluation results, the relationship behind community co-design collaborations must be sustained, or both community health outcomes and programs will suffer. As mentioned throughout this chapter, transactional researcher-community relationships break trust [17, 20]. Each instance of trust-breaking lessens the community's willingness to participate the next time and exponentially increases the amount of effort required to rebuild the relationships. Sustaining collaborative relationships between projects is not easy; it requires transitioning from transactional interactions to transformational ones.

Both internal and external factors influence sustainability of collaborations. The previous sections of this chapter emphasized the need for trust, respect, listening, and planning to address power differentials among partners and build relationships. Early decisions on who (individuals or organizations) leads the partnership,

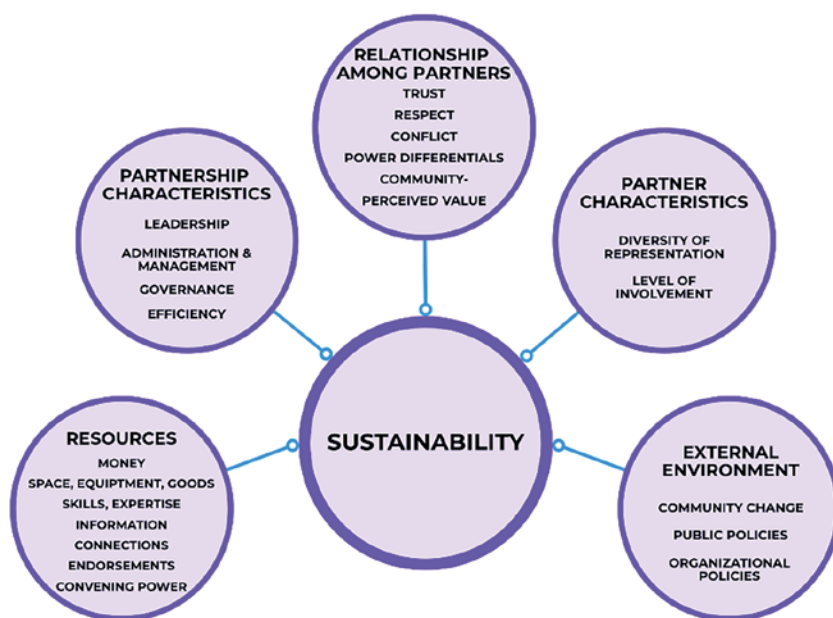


Figure 3.
Drivers of sustainability in community-engaged partnerships. Adapted from previous work by author [59].

the rationale behind that choice, and processes for decision-making and conflict resolution are essential. Partnership can affect both the daily functioning of the collaborative effort and determine whether it has the potential to continue. As the PHEN research team experienced, processes for conflict resolution can make or break a collaboration [31]. Community-engaged partnerships benefit from leaders who embrace inclusive approaches [18]. **Figure 3** [59] depicts these factors.

Partnerships change and evolve over time. Individual factors may be more or less important at different stages of development. Some research has shown that factors such as leadership, commitment, non-monetary resources, funding, and emerging needs may have more weight in the formative stages, while membership, communication, adaptability, external policies, and resources (both monetary and non-monetary) may be more important in later stages [59].

Reflecting on **Figure 1**, this chapter has focused on the community collaboration and community partners stages of the community engagement continuum, with some examples of projects on the path toward community-led initiatives. Achieving true sustainability may be dependent upon increasing structural support for community-led research and programs. This requires ongoing investment in capacity-building and significant changes in funding models, allowing funds to flow directly to community partners who would have the authority to subcontract with or provide stipends to academic researchers.

7. Challenges

Ideally, community co-design is the symbiotic merging of academic expertise and real-life experience to achieve better health outcomes and health equity. Within institutions, both governmental and educational, though, it is not always seen as

a credible research method of the same value as traditional survey or quantitative work. In a system that rewards high monetary value grants from places like esteemed scientific agencies, full indirect costs, and first author papers, community co-design grants tend to come from the smaller services-focused agencies and foundations with caps on indirect costs and the resulting papers name groups as authors; all of which can make promotions and tenure harder to achieve for community-focused researchers and function as a disincentive to pursuing actual collaborative work [4, 60, 61]. Furthermore, few academic institutions have invested in the structure, policies, and procedures necessary to support faculty and staff spending their time and effort building community trust and partnerships.

The Engage for Equity plus study [9, 13, 17, 60] found that institutions are able to move toward a model that sustains true community partnership and collaboration when institutional leaders highly value these practices, leverage existing data, and look critically at the organizational climate to design strategies that give weight to community ideas across topics. The other institutional challenge is that future public health practitioners are not being trained in principles of community-engaged work nor the intentional building and repair of relationships that is at the core of community-engaged work, including generous listening, sensitivity to lived experience, trauma-informed approaches, and respect for the diversity of people, ideas, and opinions [8, 19, 31, 42]. Failing to do this will maintain the power differential. Universities will continue to use the community to meet research goals, but the community will not use the university to build resources and capacity.

8. Discussion

There is an extensive history of community-engaged public health practice and research. Many improved health outcomes for specific populations have been achieved through collaborative projects that bridged research and community action. Yet too often, these relationships and results are not sustained. Institutional constraints, funder priorities, and competing academic demands, along with shifting social and economic dynamics within communities, interrupt progress and weaken trust. This is a problem with a solution. Public health initiatives and their positive outcomes can be sustained through the consistent practice of true partnership and community co-design. Achieving this requires both behavioral change among public health professionals and structural change within the institutions that support them. Researchers, practitioners, and institutions must develop a deeper understanding of the five principles of true partnership and commit to practicing them with consistency and humility.

Shared power and decision-making give community members an equal voice in shaping policies and interventions. The Saint Vincent's Hospital Study, the Options Study, HHI, and Harlem Strong all show different ways this principle can be enacted in real life. Transparency is shown through clear and open communication about process, decisions, and outcomes. The success of the SPARCS goal of community helming the next stage of the project is linked to transparency regarding all that is happening at the current stage. Long-term trust-building is the central nerve of true partnerships and indicates the commitment to relationship building over one-off transactions. HHI's consistent presence at community board meetings and responding to the community needs they learn about there without promoting their own agenda exhibits the long-term nature of trust-building. PHEN faculty's hitting pause and reset upon realizing that they had not

built trust within their own research team illustrates the ways a lack of trust can undermine results. Each of these examples also shows how leaning into the assets and strengths of a community can improve the initiatives and further relationships which builds the potential for sustained efforts. Fair compensation and credit-sharing are manifestations of these principles, showing equity in appreciation for the work. Within the five principles are other factors that can affect sustainability, as depicted in **Figure 3** [59]. Those factors can be both facilitators and obstacles within partnerships depending on the commitment to the principles and true partnerships, particularly when confronted with institutional challenges. Underlying changes are required before community capacity-building can become a defining feature of public health practice.

9. Recommendations

Drawing on the principles of partnership and the practice-based insights presented in this chapter, the following recommendations (**Figure 4**) call on public health entities to raise the bar for equitable collaboration.

Recommendations	Description
Institutionalized Co-Design and Community Partnership	Public health institutions should formalize co-design principles within policies, funding guidelines, and evaluation criteria. HHI's integrated approach to partnership demonstrates how an embedded structure within a school or agency can sustain engagement year-round, not only during funded projects.
Commit to Equitable Compensation and Capacity-Building	Models like PRI's Community Representative Compensation Plan provide a template for fair payment and recognition of community expertise. Every project should allocate funds for both compensation and skill development to ensure that community partners are not just participants but co-leaders.
Reimagine Authorship and Credit	Projects such as PHEN and Harlem Strong illustrate how community voices can shape interpretation and dissemination. Co-authorship, joint presentations, and shared media visibility should become standard practice to reflect true intellectual partnership.
Center Equity, Representation, and Cultural Humility	Each partnership should ask, as HHI does, "Who is missing from this conversation?" Representation, trauma-informed practices, and cultural humility must guide project design and outreach from inception to evaluation.
Invest in Relationship Infrastructure	Sustainable collaboration requires resources for ongoing engagement, relationship-building, reflection, and shared presence. The Harlem Strong coalition demonstrates how consistent, visible participation strengthens both trust and program longevity.
Practice Participatory Dissemination	Returning findings through storytelling, murals, memorials, or public forums, as modeled by HHI's TRACE collaboration, helps communities see their experiences reflected in public health narratives and policies.
Shift from Transactional to Transformational Engagement	Institutions must move beyond short-term consultation toward long-term, shared leadership. True collaboration means that communities define success alongside researchers, and that institutions remain accountable even after funding ends.

Figure 4.
Recommendations.

By committing to co-design principles, public health entities can transform current and future community collaborations from temporary relationships into lasting bidirectional partnerships capable of sustaining programs and improving equitable health outcomes.

10. Conclusion

This is a call for a new generation of researchers and practitioners to raise the bar in community partnerships. These public health professionals will understand the difference between telling, asking, engaging, and partnering with communities. The institutions they will work for will provide the support necessary to sustain those partnerships. This next iteration of community co-design is the catalyst needed to address upstream determinants of health equity and to improve population health outcomes.

In this reimagined dynamic, research design and program development are driven by community leaders rather than by funders or grant guidelines. Shared power and decision-making are demonstrated through joint control of information, data, and scientific methods. Knowledge is shared openly, data use is consensus-driven, and research processes are explained to build mutual capacity and understanding.

Methodologies for data collection, relationship-building, and participatory dissemination should be both rigorous and inclusive of nontraditional approaches that hold cultural and emotional resonance, such as collective storytelling through memorials, murals, or performance. Practices of empathy, deep listening, recovery, repair, and restoration enhance awareness of diverse interpretations of experience and facilitate progress toward equity.

Ultimately, the time and effort required to build trust must be supported by institutions that recognize the value of long-term, continuous, and coordinated relationships with communities and reward the researchers and practitioners who commit to this work.

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Section 2

Emerging Community Health Challenges and New Technology

Enhancing Role Clarity and Reducing Burnout: Implementing Interprofessional Collaboration Agreements for Physician Associates in Primary Care

Nicole Gentry

Abstract

Physician associates are essential contributors to primary care delivery, playing a key role in expanding access, alleviating workforce shortages, and improving patient outcomes. However, their effectiveness is often compromised by systemic issues such as role ambiguity, scope creep, and professional burnout. These challenges disrupt team dynamics, reduce job satisfaction, and undermine the quality of care. This chapter presents the implementation of interprofessional collaboration agreements (ICAs) as a strategic and sustainable solution to these persistent problems. ICAs are formal agreements that define clinical roles, establish communication protocols, and promote mutual accountability among care team members. Guided by the Joanna Briggs Institute Implementation Framework, this project engages stakeholders, assesses organizational readiness, and applies evidence-based change strategies tailored to the primary care setting. Key evaluation metrics include reductions in provider burnout, improvements in patient satisfaction, and fidelity to ICA protocols. Key findings from the proposed implementation suggest that formalizing ICAs enhance provider role clarity, mitigate scope creep, reduce clinician burnout, and improve patient satisfaction and care continuity in primary care settings. The proposed framework offers a replicable model for improving collaboration, reducing clinician burden, and optimizing outcomes in diverse primary care environments.

Keywords: interprofessional collaboration agreements, physician associates, burnout, scope creep, role clarity, primary care, Joanna Briggs institute implementation framework, healthcare teams

1. Introduction

The efficiency and well-being of healthcare providers are essential to achieving high-quality patient outcomes. Physician associates (PAs) play a pivotal role in

primary care by addressing workforce shortages and delivering essential services. However, systemic issues such as role ambiguity, scope creep, and burnout compromise their effectiveness and contribute to professional dissatisfaction [1, 2].

Role ambiguity arises when responsibilities are unclear or overlap with those of other team members, creating inefficiencies, interpersonal conflict, and fragmented care [3, 4]. Scope creep, or the assignment of duties beyond a PA's defined role without appropriate support, intensifies this issue and contributes to burnout, a syndrome characterized by emotional exhaustion, depersonalization, and reduced personal accomplishment [5, 6]. Burnout further disrupts team dynamics, leading to delayed care, diminished quality, and patient dissatisfaction [6, 7]. Its broader effects of ripple through the healthcare system contribute to higher turnover, lower morale, and poorer outcomes [8, 9]. A scoping review protocol for this project was preregistered via OSF to ensure methodological transparency [8, 9]. Ineffective collaboration frameworks exacerbate these challenges by failing to support team navigation in complex clinical environments [10, 11]. A systematic review by Sangaleti et al. identified that unclear decision-making and insufficient communication often undermine interprofessional team performance [12]. This project proposes implementing interprofessional collaboration agreements (ICAs) in federally qualified health centers (FQHCs) and rural clinics, where provider shortages make role clarity and collaboration especially critical [13, 14]. Although PAs are highly trained, the lack of formal support structures can hinder their performance. Research supports collaborative frameworks that clarify roles, streamline workflows, and enhance team decision-making [15, 16]. ICAs offer a viable solution to reduce burnout, improve functionality, and elevate care delivery [14, 17].

Grounded in the Joanna Briggs Institute (JBI) Implementation Framework [18] and a supporting scoping review [16], this chapter introduces a sustainable ICA model tailored for primary care. This approach addresses systemic barriers to role clarity and professional satisfaction, both essential to a thriving healthcare workforce.

2. Defining the practice area and evidence-based implementation model

PAs are integral to primary care, providing a broad spectrum of clinical services, especially in underserved and high-demand areas where they are often primary providers. Despite their crucial role, systemic challenges can hinder their efficiency [19, 20]. The status quo in many primary care settings features informal role definitions, leading to inefficiencies and increased stress due to tasks performed outside their scope and inadequate communication [20]. The proposed implementation of ICAs addresses these issues by providing a structured framework for interprofessional collaboration, clearly defining roles, establishing accountability, and promoting equitable workload distribution among team members (see **Table 1**). For instance, as outlined in **Table 1**, collaborative management of chronic conditions like diabetes and rapid responsibility allocation in emergencies will be enhanced [21, 22]. These improvements are also aligned with chronic disease surveillance goals outlined in statewide public health guidance [23]. Implementing ICAs is anticipated to improve team dynamics, reduce stress, and foster a collaborative culture, leading to higher-quality and more sustainable primary care delivery [6, 19]. The model's emphasis on sustainability and trustworthiness also aligns with best practices in health research and qualitative evaluation [24, 25]. Furthermore, AB 890 offers a valuable policy precedent for expanding provider roles under formalized frameworks [26].

Stakeholder group	Roles and contributions
Physician associates (PAs)	Central to ICA implementation; address role ambiguity, burnout, and scope creep; contribute structured feedback to strengthen role clarity and sustainability.
Physicians	Collaborate in defining responsibilities and ensuring equitable task distribution. Support ICA adoption through educational workshops to improve teamwork and reduce workloads.
Clinic administrators	Oversee resource allocation, training, and outcome tracking. Use real-time monitoring tools to integrate ICAs into clinical workflows effectively.
Patients	Provide feedback through surveys and focus groups to evaluate ICA effectiveness, highlighting improvements in care coordination and satisfaction.
Organizational leaders	Align ICA objectives with strategic goals, secure funding, and advocate for policy changes to ensure institutional support and progress toward quality benchmarks.
Interdisciplinary team members	Include nurses, medical assistants, and admin staff. Assist in ICA rollout, provide feedback, and benefit from training to promote acceptance and reduce resistance.
AAPA and CAPA	AAPA advocates for ICAs nationally; CAPA addresses implementation challenges at the state level, advancing collaborative practice for PAs.
NCQA and AMA	NCQA develops evaluation standards for ICAs; AMA fosters physician collaboration and addresses scope of practice concerns.
Public health agencies	Ensure ICA implementation aligns with public health goals, supporting population health at federal, state, and local levels.
CDC and NIH	CDC supports ICAs in preventive and chronic disease care; NIH evaluates ICA outcomes through evidence-based research.
FQHCs and community clinics	Tailor ICAs to fit diverse and resource-limited environments, promoting culturally competent, patient-centered care across rural and urban areas.

AAPA = American Academy of Physician Associates; CAPA = California Academy of PAs; NCQA = National Committee for Quality Assurance; AMA = American Medical Association; CDC = Centers for Disease Control and Prevention; NIH = National Institutes of Health; ICA = Interprofessional Collaboration Agreement; PA = collaborating Physician Associate; FQHC = Federally Qualified Health Center.

Table 1.
Stakeholder Groups, Roles, and Contributions.

3. Key stakeholders

Successful ICA implementation depends on the active engagement of key stakeholders across all organizational levels. Physician associates (PAs), physicians, administrators, interdisciplinary team members, patients, public health agencies, and advocacy organizations each bring essential perspectives, resources, and decision-making authority. Their participation ensures that ICAs are aligned with clinical workflows, institutional goals, and patient needs. **Table 1** summarizes stakeholder roles and contributions across the implementation process.

4. Communication channels, committees, and reporting requirements

Strong communication channels provide the foundation for successful ICA implementation. Internal meetings, such as weekly huddles and monthly leadership updates, play a critical role in ensuring alignment across teams and addressing emerging challenges promptly. These meetings allow real-time problem-solving

and reinforce shared accountability among stakeholders. Digital platforms, enhance collaboration by centralizing resources, tracking progress, and facilitating real-time communication among geographically dispersed team members [20].

4.1 Engagement and oversight committees

Patient feedback mechanisms, including surveys and focus groups, are another vital communication tool, offering valuable insights into care quality and satisfaction from the patient perspective. This input informs ICA refinement and supports a patient-centered approach to care delivery [21].

4.2 Patient feedback and oversight committees

Patient input is a key component of ICA refinement. Surveys and focus groups provide valuable insights into care quality and satisfaction, supporting a patient centered, responsive approach to delivery [21].

To ensure structured implementation and accountability, several oversight committees guide ICA rollout:

- **Implementation Steering Committee:** Provides strategic direction, allocates resources, and addresses system-level barriers [27].
- **Interdisciplinary Collaboration Committee:** Promotes team cohesion, resolves conflicts, oversees the design, implementation, and ongoing updates of ICA protocols based on stakeholder feedback [23, 24].
- **Audit and Quality Improvement Committee:** Conducts regular audits to monitor compliance, assess outcomes, and inform ongoing improvement [19, 24].

Together, these mechanisms foster continuous feedback and ensure that ICAs remain adaptable, effective, and aligned with both organizational goals and patient needs.

5. Engage change agents

Successful ICA implementation depends on the coordinated efforts of three key leadership roles:

- **System leaders** (e.g., CMOs, lead PAs) align ICA efforts with organizational priorities, advocate for resources, and ensure institutional support [22, 27].
- **Technical experts** provide clinical and regulatory guidance to ensure ICA protocols are safe, compliant, and evidence based [20].
- **Day-to-day leaders**, such as clinic or unit managers, integrate ICAs into daily workflows, troubleshoot operational issues, and sustain staff engagement [20, 21].

Together, these change agents bridge strategy and execution, supporting the consistent and sustainable rollout of ICAs across settings.

6. Project management

Project management provides the structure and coordination necessary for successful ICA implementation across multiple stakeholders and settings.

6.1 Team structure and coordination

A resolute project manager plays a central role in overseeing clinic operations, managing timelines, allocating resources, and maintaining communication among stakeholders. This coordination ensures ICA implementation stays on track and responsive to emerging challenges [23].

The broader project team comprised of clinic representatives, technical experts, and leaders across organizational levels meets regularly to monitor progress, promote transparency, and refine strategies. Iterative improvement methods, such as the plan-do-study-act (PDSA) cycle, support continuous alignment with organizational goals and facilitate adaptive implementation [24, 25].

6.2 Monitoring and evaluation framework

A robust monitoring framework enables continuous evaluation of ICA implementation by tracking key performance indicators (KPIs), including role clarity, provider burnout, and care quality. In alignment with evidence-based models, these indicators are categorized by implementation stage [14]. *Inputs* include factors such as training availability and leadership engagement. *Processes* refer to metrics like the number of ICAs signed and adherence to established protocols. *Outcomes* capture results such as reductions in provider burnout [1], improvements in role clarity, and increases in patient satisfaction measured by CAHPS surveys [26]. *Effects* reflect long-term impacts, including improved clinical outcomes (e.g., A1c, LDL, and hypertension control [23, 24]), reduced delays in care, and higher workforce retention rates. Real-time dashboards and quarterly audits, stratified by provider role, enable timely, data-driven adjustments and support sustained improvement.

7. Facilitator of change at the point of practice

At the practice level, a dedicated facilitator plays a crucial role in translating strategic goals into operational execution. This responsibility is often assigned to individuals such as lead PAs, clinic site leaders, or clinic managers who have the expertise and established relationships necessary to guide change effectively.

Facilitators are selected for their deep understanding of clinical workflows and team dynamics, which allows them to offer practical, context-specific guidance. Their trusted relationships with staff help build credibility, promote buy-in, and reduce resistance to change [20]. Strong communication skills enable facilitators to articulate objectives, address concerns, and deliver actionable feedback, fostering collaboration [21].

Their commitment to quality improvement is evident through initiative-taking problem-solving and advocacy throughout the implementation process. Skilled in conflict resolution and team motivation, facilitators help navigate challenges and drive adoption of new practices. By combining technical knowledge, leadership, and interpersonal strengths, they ensure consistent engagement and effectively support ICA integration across settings [24].

8. SWOT analysis and organizational readiness

8.1 Readiness for ICA implementation

Organizational readiness plays a central role in the successful adoption of ICAs. A synthesis of stakeholder input, environmental context, and findings from the scoping review revealed strengths such as quality improvement infrastructure and collaborative team culture. However, significant barriers were identified, including rigid structures, limited leadership opportunities for PAs, top-down communication, and inadequate PA representation in decision-making. These factors impact implementation effectiveness and must be addressed through improved workflow adaptability, bidirectional communication, and leadership development. A full summary of organizational strengths, weaknesses, opportunities, and threats is presented in **Table 2**.

8.2 Structure

The organization maintains established systems for quality improvement, offering a strong foundation for ICA adoption. However, rigid structures, particularly those limiting PA involvement in leadership can delay decision-making and constrain

Category	Strengths	Weaknesses	Opportunities	Threats
Structure	Established framework supports quality improvement and ICA introduction.	Lack of flexibility leads to resistance and delays, especially for integrating PAs into leadership roles.	Streamlining workflows and optimizing team structures for inclusiveness and adaptability.	Rigidity and exclusion of PAs from key roles may hinder timely ICA implementation.
Workplace culture	Collaborative culture facilitates ICA adoption.	Resistance to change and inadequate inclusion of PAs in leadership affect engagement.	Engaging PAs as champions to improve ICA perceptions and gain team buy-in.	Resistance to PA inclusion in leadership roles may slow implementation and be perceived as disruptive.
Communication	Multiple communication channels (meetings, newsletters, digital platforms) aid information flow.	Primarily top-down communication limits PA feedback and engagement.	Enhancing bidirectional communication to improve adaptability and responsiveness.	Lack of inclusive communication and feedback may result in miscommunication and disengagement.
Leadership	Leadership supports quality improvement and evidence-based practice initiatives.	Insufficient PA representation in leadership affects oversight and ICA support.	Training and leadership development for PAs to ensure equal opportunities and sustain ICA integration.	Lack of focus on developing PAs as leaders could disconnect leadership goals from implementation efforts.

ICA = Interprofessional collaboration agreement; PA = Physician associate.

Table 2.
Contextual factors for change (SWOT analysis).

innovation. Promoting workflow flexibility and inclusive leadership pathways can enhance structural readiness [14, 17].

8.2.1 Workplace culture

A collaborative and collegial workplace environment supports the principles of interprofessional care. Still, cultural resistance to expanding PA leadership involvement persists. Positioning PAs as facilitators of change and active contributors to implementation efforts can reduce this resistance and increase alignment with ICA goals [6, 7, 13].

8.2.2 Communication

Although the organization uses regular meetings and digital platforms for information sharing, communication remains top-down. This structure limits the ability of frontline team members, including PAs to offer input. Creating more inclusive and bidirectional communication channels is essential to build trust and foster shared ownership of ICA processes [1, 2, 21].

8.2.3 Leadership

Leadership demonstrates commitment to evidence-based practice and improvement initiatives. However, the lack of PA representation in strategic decision-making roles limits full integration. Strengthening leadership development opportunities and formal mentorship structures can address this gap and improve oversight of ICA implementation [10, 11, 23].

9. Review evidence-based audit criteria and sampling plan

9.1 Population to sample

PAs are central stakeholders of ICAs, providing direct insights into role clarity, burnout, and satisfaction [1, 9].

9.2 Sampling strategy

A stratified random sampling approach will be employed, selecting clinics from varying geographic and demographic contexts to ensure representativeness and diversity [10, 13].

9.3 Time, budget, and support

The baseline audit will require 3 months to minimize disruption to clinic operations while allowing thorough data collection. Adequate budget allocations and organizational support are essential to maintain operational continuity [19, 20].

9.4 Bias mitigation

To ensure validity and reliability, several strategies will be employed to mitigate bias:

- Standardized tools: Instruments such as the Maslach Burnout Inventory (MBI) and the Consumer Assessment of Healthcare Providers and Systems (CAHPS) will be administered uniformly across sites [1].
- Credibility in qualitative analysis: To enhance trustworthiness, qualitative data will be coded independently by multiple researchers. A consensus-based approach and established rigor criteria—credibility, confirmability, and dependability—will be used to reduce observer bias and strengthen analytic validity [6, 27].

To ensure validity and reliability, several strategies will mitigate bias:

- Randomization: Clinics will be selected using random stratification, reducing selection bias [25].
- Standardized tools: Instruments such as the MBI and Consumer Assessment of Healthcare Providers and Systems (CAHPS) can be used uniformly across sites [1, 28].
- Credibility in qualitative analysis: To enhance trustworthiness, qualitative data will be coded independently by multiple researchers. A consensus-based approach and established rigor criteria, credibility, confirmability, and dependability, will be used to reduce observer bias and strengthen analytic validity [25].

10. Data collection methods

A mixed-methods approach will comprehensively evaluate ICA implementation, combining quantitative and qualitative strategies:

10.1 Surveys and questionnaires

Tools like the *Maslach Burnout Inventory (MBI)* will assess burnout and job satisfaction among PAs and team members [1], while role clarity will be evaluated using metrics identified in recent interprofessional collaboration research [6, 7].

Patient satisfaction surveys, such as CAHPS, will evaluate care quality and accessibility [28].

10.2 Patient outcome metrics

Chronic disease indicators (e.g., A1c levels, LDL cholesterol, and hypertension metrics) will provide objective measures of care quality and team collaboration [3].

10.3 Interviews and focus groups

Semi-structured interviews with PAs and clinic leaders will identify barriers and enablers of ICA implementation.

Focus groups will explore themes such as interprofessional dynamics and workflow challenges [1].

10.4 Document review

Reviewing existing collaborative agreements and team-based care models will provide a baseline for comparison with the proposed ICA framework [1, 10, 22].

10.5 Examples from literature

Supper et al. demonstrated the effectiveness of focus groups in evaluating inter-professional collaboration [3].

Edwards and Landon confirmed the use of burnout and satisfaction metrics as reliable tools for understanding team dynamics [1].

11. Implications for practice

The results of this audit will offer critical insights into the strengths and challenges of ICA implementation. It will highlight how ICAs influence role clarity, burnout, and patient outcomes across diverse primary care settings. Furthermore, the findings will inform tailored interventions to address barriers, improve workflows, and promote sustainable interprofessional collaboration.

12. Implement changes using GRiP (getting research into practice)

The GRiP model, developed by the Joanna Briggs Institute (JBI), provides a structured framework for translating evidence into practice [14]. This section outlines how each of the four GRiP components informs the implementation of Interprofessional Collaboration Agreements (ICAs) across diverse underserved healthcare settings, ranging from federally supported and rural clinics to low resource and community-based facilities globally. The adaptable nature of this model makes it applicable across various health systems, cultural contexts, and care delivery environments.

12.1 Evaluate baseline audit findings

A formal baseline audit was not conducted due to logistical constraints and the research-based nature of this project. Instead, a comprehensive literature review served as the foundation for establishing contextual insights into PA leadership integration and the utilization of ICAs in primary care [9].

This literature-informed analysis identified several recurring system-level challenges:

- Limited PA representation in leadership roles, despite their growing clinical contributions in underserved settings [1, 10, 12].
- Absence of structured ICAs, contributing to role ambiguity, scope creep, and inconsistent team collaboration [1, 14].
- Implementation shortcomings in existing interventions, which often prioritize clinical task delegation without addressing leadership development, staff well-being, or long-term outcome monitoring [1, 14].

These findings informed the strategic design of the proposed ICA implementation model. Although not yet piloted, the model is grounded in these well-documented barriers and aims to introduce a structured, evidence-based framework to strengthen role clarity, reduce provider burnout, and enhance quality of care within primary care settings globally.

12.2 Identify barriers and enablers

The following barriers and enablers were identified through the scoping review, stakeholder input, and assessment of current practice environments [9]:

Barriers

- Limited leadership opportunities for PAs [10, 12, 13]
- Organizational resistance to change [13, 14]
- Burnout related to workload imbalances and lack of institutional support [1, 14]
- Role ambiguity and scope creep, leading to inefficiencies [14]
- Insufficient tracking and limited use of analytics tools [12, 14]
- Resource constraints in rural and underserved clinic settings [12, 24]

Enablers

- Legislative support in California and other states for formalizing ICA use [12]
- Documented improvements in chronic disease outcomes through structured ICAs [13, 14]
- Advancements in telehealth that enhance care team collaboration, especially in underserved and remote settings [24]
- Organizational commitment to equity and access in FQHCs and similar clinics, aligning with ICA goals [12, 24]
- International evidence supporting ICA use across diverse healthcare systems, demonstrating improvements in primary care delivery, patient outcomes, and collaboration among interdisciplinary team members and clinical staff [6, 8, 12, 14, 27]

This barrier-enabler analysis is essential for shaping implementation strategies that address the specific needs of primary care teams. Insights from international studies, including those from Australia, the United Kingdom, and Canada, which highlight additional enablers such as national policy alignment, interprofessional education, and integrated care models, all of which support broader ICA adoption [15, 16, 19]. Incorporating these global findings enhances the relevance and adaptability of the proposed framework across diverse healthcare systems (**Table 3**).

Barrier	Resources	Outcomes	References
Limited leadership opportunities	Educational outreach and leadership development programs for PAs	Enhanced leadership representation among PAs, fostering professional growth	[9, 10, 23]
Organizational resistance	Consensus-building sessions, educational initiatives, leadership support	Stakeholder meetings to build collaboration and organizational buy-in and reduced resistance to ICAs	[17, 23, 26]
Burnout due to workload imbalances and lack of support	Wellness resources, flexible scheduling tools, burnout tracking surveys	Reduced emotional exhaustion and increased job satisfaction among PAs	[1, 14, 23]
Role ambiguity and scope creep	ICA templates, role-specific training sessions	Improved role clarity, reduced overlapping responsibilities, and enhanced team collaboration	[14, 17, 25]
Insufficient patient outcome tracking	EHR upgrades, analytics software, staff training in data utilization	Measurable improvements in patient outcomes and streamlined care delivery	[12, 14, 23]
Resource constraints in rural clinics	Telemedicine platforms, grant-writing resources, partnerships with nonprofits	Enhanced healthcare access and equitable resource allocation in underserved areas	[12, 23, 24]

ICA = Interprofessional collaboration agreement; PA = Physician associate; CPCA = California primary care association; CDPH = California department of public health; EHR = Electronic health record.

Table 3.
Barriers and strategies for implementation of change.

12.3 California case example: A scalable ICA implementation model

California's FQHCs offer a compelling example of effective implementation of ICAs. With policy backing from the California Primary Care Association (CPCA) and the state has enabled expanded roles for nurse practitioners through Assembly Bill 890 and has promoted integrated, team-based care models. Backed by CPCA, California's AB 890 expanded nurse practitioner scope and can provide a replicable model for incorporating advanced practice practitioners (APP) into team-based care using Interprofessional Collaboration Agreements (ICAs) to support safe, independent practice within defined parameters. This policy shift removes longstanding practice barriers for NPs and strengthens the legal and operational foundation for formal ICA implementation, particularly in rural and underserved communities [23, 26].

These developments are reinforced by the state's chronic disease surveillance and outcome monitoring infrastructure led by the California Department of Public Health (CDPH) [24], which enables continuous tracking of key quality metrics such as A1c, LDL cholesterol, and blood pressure outcomes aligned with ICA-driven care goals [24].

While these strategies have been developed within the unique healthcare landscape of California, they offer a scalable, evidence-based model that other organizations can adapt. The integration of supportive legislation, care delivery innovation, and institutional leadership development directly aligns with the third phase of the GRiP model Develop and Implement Strategies for Change and serves as a model framework for replication in FQHCs and rural clinics nationwide.

12.3.1 Broader support for ICA implementation across settings

The proposed ICA model builds on a structured scoping review that identified widespread support for interprofessional collaboration to improve care in primary care environments. While ICAs are recognized as valuable tools, formal implementation protocols, especially within FQHCs, remain underreported [9, 12, 13]. Studies across the U.S. and internationally have demonstrated positive outcomes from structured collaboration models, including improved chronic disease management, enhanced team dynamics, and reduced provider burnout [3, 8, 10, 15]. These findings reinforce the relevance and global applicability of the proposed ICA framework, particularly in resource-constrained and underserved settings.

12.3.1.1 Clarity on implementation strategy

The proposed ICA implementation strategy follows a structured, evidence-based process to promote sustainable integration into primary care settings. Initial preparation involves engaging stakeholders, finalizing ICA templates customized to organizational workflows, and conducting education sessions for clinical teams [14, 23]. During the implementation phase, clinics will formalize and sign ICA agreements, update EMR templates for documentation alignment, and establish team huddles to reinforce role clarity and communication [23, 27]. Monitoring and evaluation activities will include quarterly audits of role clarity, burnout, and patient satisfaction, with real-time dashboards to provide feedback and guide mid-course corrections [25]. Sustainability planning will incorporate periodic reassessment of workflows, leadership training for physician associates and interdisciplinary team members, and updates to ICA structures based on evolving clinical needs and policy changes [14, 25]. By combining preparation, structured rollout, iterative feedback, and continuous adjustment, the strategy reflects implementation of science best practices and addresses known barriers to sustainable collaboration identified in prior studies [14, 25, 27].

12.4 Reassess the change and plan for sustainability

A comprehensive sustainability and reassessment plan is essential to ensure that ICA implementation remains effective, adaptable, and responsive to evolving clinical needs. Key strategies include:

- Internal surveys: Conduct biannual assessments of staff burnout, satisfaction, and role clarity using validated tools such as the Maslach Burnout Inventory (MBI) [1, 22].
- Patient surveys: Use CAHPS or comparable tools on a quarterly basis to assess care quality and patient experience [22, 23].
- Chronic disease metrics: Continuously monitor A1c, LDL cholesterol, and blood pressure control through EHR-based analytics, with flexibility to adjust metrics according to practice focus [22, 23].
- Feedback loops and audits: Implement scheduled audits and feedback sessions to identify improvement areas and support iterative refinement.

- **Structured timeline:** Follow a phased approach that includes baseline assessments, midpoint reviews, post-implementation audits, and scale-up activities.

To guide sustainability and facilitate replication across varied care settings, the full sequence of implementation milestones is outlined in **Table 4** and further detailed in **Table 5** ICA Implementation and Replication Checklist. This structured timeline, from initial stakeholder engagement through long-term reassessment, supports ongoing progress while allowing flexibility based on performance data and stakeholder input.

Phase	Activities	Timeline	Responsible Parties
Phase 1: preparation	Finalize ICA framework, identify target clinics, and engage key stakeholders.	Month 1	Implementation of steering committee
	Conduct baseline data collection on role clarity, burnout rates, patient satisfaction, and chronic disease metrics.	Months 2–4	Audit & quality improvement committee
	Conduct workshops and training sessions to familiarize PAs, physicians, and team members with ICA protocols.	Month 3	Interdisciplinary collaboration committee
Phase 2: implementation	Implement ICAs in selected clinics as a research-based model program, emphasizing role clarity and interprofessional collaboration frameworks.	Months 5–12	Clinic administrators & day-to-day leaders
	Weekly or bi-weekly team huddles and leadership updates to address challenges and monitor progress.	Months 5–12	Clinic administrators
	Review preliminary data and address emerging barriers through feedback loops with stakeholders.	Month 8	Steering committee & audit team
Phase 3: re-assessment	Reassess burnout, patient satisfaction, and chronic disease metrics using surveys and EHR tools.	Month 12	Audit & quality improvement committee
	Compare baseline data with follow-up results to measure ICA impact.	Month 13	Audit team
	Share findings with stakeholders and identify adjustments needed for improvement.	Month 14	Steering committee
Phase 4: sustainability	Revise ICA protocols and workflows based on feedback and audit findings.	Month 15	Interdisciplinary collaboration committee
	Develop policies and leadership training programs to sustain ICAs long-term.	Months 16–18	Organizational leaders
	Conduct targeted training for PAs to prepare them for expanded leadership roles.	Months 16–18	Training & leadership development team
	Reassess key metrics (burnout, satisfaction, chronic disease outcomes) to validate sustainability.	Month 24	Audit team

Phase	Activities	Timeline	Responsible Parties
Phase 5: scale-up	Identify successful elements of ICA implementation for replication in additional clinics.	Months 25–27	Steering committee
	Develop a phased rollout plan for scaling ICAs across additional FQHCs and rural clinics.	Months 28–30	Steering committee & clinic administrators
	Begin ICA implementation with adaptations if any, in newly identified clinics while providing ongoing support.	Months 31–36	Day-to-day leaders & regional administrators

ICA = Interprofessional Collaboration Agreement; PA = physician associate; EHR = Electronic Health Record; FQHC = Federally Qualified Health Center.

Table 4.
Proposed timeline for re-assessment, sustainability, and scale-up of ICAs.

13. Conclusion

By addressing systemic barriers and leveraging key enablers, this model offers a research-informed, scalable approach to bridging the evidence-to-practice gap. It supports the elevation of PAs as collaborative leaders in primary care, particularly in rural and underserved settings. This structured timeline for reassessment, sustainability, and scale-up (**Table 4**) ensures adaptability over time.

Rather than endorsing a single standardized ICA, this review emphasizes core elements, such as team identification, defined roles, and scopes of practice based on

Phase	Step	Action item	Goal
Preparation	1	Engage stakeholders, including PAs, physicians, administrators, and patients	Build buy-in and collaboration commitment
Preparation	2	Customize standard ICA template to reflect local licensure and workflow needs	Preserve standard principles; adapt to setting
Education	3	Conduct team education sessions introducing ICA goals, structure, and benefits	Promote understanding and commitment
Execution	4	Formalize and sign ICA agreements among all care team members	Establish clear scopes of practice and mutual accountability
Integration	5	Update EMR templates to support ICA tracking and hand-off documentation	Ensure operational alignment and monitoring
Monitoring	6	Launch patient satisfaction surveys at baseline and 3 months post-implementation	Monitor patient care perceptions and improvements
Monitoring	7	Conduct quarterly team reviews assessing burnout levels, role clarity, patient outcomes	Sustain momentum and address emerging barriers
Sustainability	8	Perform annual ICA update based on audit findings, clinical trends, and legislative changes	Maintain model relevance, support workforce resilience

ICA = Interprofessional Collaboration Agreement; EMR = Electronic Medical Record; PA = Physician Associate; KPI = Key Performance Indicator; CAHPS = Consumer Assessment of Healthcare Providers and Systems; MBI = Maslach Burnout Inventory.

Table 5.
ICA implementation and replication checklist.

licensure, education, and experience, that remain consistent across systems [10, 13, 14]. ICA formatting is intentionally flexible to accommodate local policies, work-flows, and evolving clinical demands [14, 17, 22].

This adaptability reinforces the value of ICAs as policy-relevant tools for promoting collegial, team-based care. Evidence from international settings highlights their potential to reduce burnout, limit scope creep, and improve workforce retention in resource-constrained environments [6, 12, 13, 22]. When implemented strategically, ICAs help optimize PA roles and foster a collaborative and respectful practice culture.

Although not yet piloted by the author, this model is grounded in a structured scoping review and supported by implementation science. It addresses urgent workforce challenges through formal, sustainable strategies for improving care delivery and team collaboration.

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Nomenclature

ICA	interprofessional collaboration agreement
PA	physician associate
FQHC	federally qualified health center
GRiP	getting research into practice (JBI model for evidence implementation)
SWOT	strengths, weaknesses, opportunities, threats
JBI	Joanna Briggs Institute
MBI	Maslach Burnout Inventory

CAHPS	consumer assessment of healthcare providers and systems
EHR	electronic health record
CPCA	California Primary Care Association
CDPH	California Department of Public Health
AAPA	American Academy of Physician Associates
CAPA	California Academy of Physician Associates
NCQA	National Committee for Quality Assurance
AMA	American Medical Association
CDC	centers for disease control and prevention
NIH	National Institutes of Health
NP	nurse practitioner
APP	advanced practice practitioner

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Chapter 6

Intersectional and Systems-Based Community Health: Lessons from Climate Resilience, Migration, and Health Equity

Lilanga Hasini Fernando Batawalage

Abstract

This chapter examines how intersectional and systems-based methods can transform community health strategies to better address the complex realities of climate change, migration, and health inequalities. Using case studies and policy insights, it explores how intersecting social determinants, such as race, gender, legal status, and geography, interact with structural systems to influence health outcomes. It promotes resilience-building through co-produced, equity-driven frameworks that incorporate lived experience and intersectoral collaboration. By connecting public health practice with climate resilience and migration-informed strategies, the chapter provides a forward-looking approach for inclusive, adaptable, integrated, and justice-centred community health systems in response to increasing global challenges.

Keywords: intersectionality, health equity, systems thinking, climate and migration, community health models

1. Introduction

Community health today faces a time of reckoning. Once defined as the health status and well-being of the concept of ‘people in a specific area’, often evaluated through disease rates, service availability, or prevention initiatives, it now seems too limited [1, 2]. The twenty-first century has revealed the shortcomings of traditional models. Climate change, global migration, and growing inequalities are redefining what it means to be healthy, where health is produced, and who influences health systems. Community health must now be viewed as interconnected with broader social, economic, ecological, and political systems. Conventional methods are inadequate for addressing today’s complex, interconnected issues, making it essential to adopt intersectionality and systems thinking to develop deeper solutions.

Originating from Black feminist theory, intersectionality demonstrates how racism and sexism are intertwined, not separate [3]. In health, it clarifies how social identities, like gender, race, class, migration status, and disability, do not operate independently but merge, often leading to compounded marginalisation and

risks [4, 5]. A migrant woman of colour experiencing poverty and language barriers faces not only obstacles but also exists within systems designed to benefit others.

Systems thinking complements this perspective by recognising patterns, feedback loops, delays, and complexity [6]. Its influence in public health has grown, especially in place-based interventions and resilience-building efforts [7]. It enables communities and practitioners to look beyond superficial symptoms to underlying causes, demonstrating how change in one area can ripple outward.

Why are these approaches crucial now? We face three intersecting forces demanding new responses: climate change, migration, and health inequality. Each reshapes community health, creating an interconnected crisis.

Climate change is already affecting daily life, work, and health and well-being. Heatwaves, floods, pollution, food system disruptions, and changing disease patterns impact health in both expected and unforeseen ways. These impacts are felt disproportionately: marginalised, insecurely housed, or discriminated-against communities are most vulnerable, with limited resources to adapt [8, 9]. In many places, the climate crisis adds to historical injustices. Overburdened, underfunded local health systems are asked to do more with less and to plan for an uncertain future.

Migration adds further complexity. Whether crossing borders or moving within countries, migration significantly affects health systems. Migrants are often perceived as burdens rather than assets, yet they are crucial to local economies and healthcare. They contribute knowledge, networks, and resilience strategies that strengthen communities. The issue is not migration itself, but how systems handle it. Exclusion from healthcare, cultural misunderstanding, trauma, and data invisibility are common issues [10, 11], reflecting deeper political and structural failures.

Health inequalities have long been recognized, yet they continue to persist—and in many cases, are getting worse. Despite years of research and policy initiatives, disparities remain. Marginalised groups face shorter life expectancy, higher rates of chronic illness, and worse mental health outcomes [12, 13]. This is not just about access but about system design—who is prioritised, what values are embedded, and whose voices are heard or ignored. Without addressing these systemic issues, equity remains just a slogan.

Climate change, migration, and inequality are interconnected through systemic, cumulative, and personal impacts. These issues manifest in neighbourhoods, clinics, schools, and daily decisions related to safety, care, and survival. They are felt unevenly, with some communities bearing heavier burdens. Yet, these communities are also sources of strength, innovation, and resistance.

This chapter advocates for a new community health approach, rooted in intersectionality as a core lens, not an addition. It calls for systems thinking to guide practical action amid interconnected challenges. The approach should prioritise lived experiences, empower communities, and be adaptable enough to respond to disruptions while maintaining justice.

The chapter then outlines a framework for such an approach, illustrated through examples in climate adaptation, migrant health, and equity-focused practices. It highlights how communities are already experimenting with new methods and proposes principles for building inclusive, resilient health systems prepared for future challenges. The goal is to move beyond merely closing gaps towards reimagining community health amid crisis and change.

A transformative shift in community health systems is essential to address the overlapping crises of inequality, climate change, and systemic exclusion.

2. Conceptual foundations

Intersectionality and systems thinking are more than just buzzwords; they are valuable tools that help us grasp complex issues. Both originate from different realms—one from social justice activism and critical theory, the other from environmental science and organisation studies. Yet, they both encourage us to look beyond individual problems to identify underlying patterns.

Crenshaw, a legal scholar, originally theorised intersectionality, highlighting how Black women face marginalisation not only through racism or sexism but through their intersection [3]. In public health, this concept has been expanded to explore how multiple social identities, such as race, gender, class, migration status, sexuality, and disability, interact to create unique risks and injustices [4, 5, 14]. It is not simply about adding categories but understanding how systems of power shape health outcomes in multi-layered ways.

Research indicates that neglecting intersectionality results in blind spots. For example, health services designed for ‘women’ often overlook the needs of transgender women or migrant women with insecure status. Similarly, equity audits focused on ethnicity might miss how class, geography, and disability amplify risk. An intersectional perspective insists that health equity must reflect real lives, not just statistical averages [4, 15].

Systems thinking offers a different perspective, but arrives at similar insights. It prompts us to explore how parts of a system interact. In health, this means understanding how housing, education, transport, employment, and social norms impact outcomes. Meadows described systems as having leverage points: places where a small change can trigger significant, lasting effects [6]. However, identifying these points requires a comprehensive understanding of the entire system.

Public health has begun integrating systems thinking more deliberately. Complex interventions in specific settings now utilise tools like causal loop diagrams, stakeholder mapping, and scenario planning [7, 16]. These methods help identify feedback loops, unintended consequences, and cross-sector opportunities. For example, in climate adaptation, systems tools are used to prepare for overlapping risks like heatwaves, flooding, and food insecurity, and how these interact with housing, income, and health services [17].

Importantly, both intersectionality and systems thinking challenge reductionist views. They oppose the idea that complex problems can be solved with simple solutions. Instead, they embrace complexity and encourage us to work with it. Though this approach is not easy, it is vital.

Together, these approaches provide a foundation for reimagining community health. They inspire new questions: who is most affected and why? What underlying patterns exist? How do solutions in one area influence outcomes elsewhere? Most importantly, how can we develop systems that are fair, adaptable, and centred on the most at-risk populations?

3. Climate resilience and community health

Climate change now poses a major public health emergency, impacting lives, shifting risks, and deepening inequalities. Events like floods, heatwaves, vector-borne diseases, disruptions to food systems, and air pollution often intersect with fragile healthcare services, displacing populations and straining resources [8, 18, 19]. The

effects are uneven; those in poverty, insecure housing, or informal settlements face heightened risks due to historical neglect and systemic exclusion rooted in intersecting power structures [4, 5].

Research increasingly confirms that social determinants of health significantly shape climate hazards. Floods devastate already overcrowded and underfunded communities, while heatwaves are especially deadly for those without cooling, green spaces, or strong community networks [20, 21]. Vulnerabilities linked to migration, gender, race, age, and disability influence both exposure and resilience [5, 14].

Framing climate resilience as only technical preparedness is no longer viable. Growing evidence supports community-based, equity-focused approaches that leverage lived experience and systems thinking. For example, participatory adaptation projects in urban slums show improved infrastructure, trust, and accountability when residents help gather flood data and collaborate with planners [22].

Ayers and Forsyth state that community adaptation works best when it actively involves local power structures and marginalised groups, ensuring strategies are not just technically sound but also fair and legitimate [23]. In the UK, local authorities working with community organisations have extended heat-health alerts and engaged residents through trusted channels, enabling timely messages and shared ownership of health initiatives [24].

Health systems must also evolve. A recent global review indicates that while many national health plans mention climate adaptation, few embed it into routine services [25]. Gaps remain in training, infrastructure, early warning systems, and cross-sector cooperation. Nonetheless, successful examples exist, such as climate-resilient health facilities in Ghana that incorporate solar power, early warning systems, and community outreach for vector control and water safety [26]. Similar participatory efforts in low-income urban areas, like community-led flood monitoring in informal settlements, show that technical resilience combined with citizen engagement enhances infrastructure and institutional trust [22, 27].

Equity must remain central, ensuring power and voice are preserved; otherwise, climate adaptation risks worsening inequality. Evidence shows that funding often skips marginalised communities or disregards informal residents in formal planning [28]. An intersectional perspective considers whose health and participation are prioritised and who is represented in data.

As climate change accelerates, resilience should mean more than recovery—it must involve transformative change. Communities already experiment with integrating environmental, social, and health resilience. Examples include women-led mangrove restoration in Bangladesh and community-driven heat vulnerability mapping by migrant workers in Europe, challenging siloed approaches and empowering collective agency [29, 30].

This chapter advocates that community-based climate resilience in health rests on three pillars: acknowledging intersectional risks, co-creating knowledge and solutions, and developing adaptable yet equitable systems. Only then can resilience transcend mere survival and become a pathway towards equity and renewal.

4. Migration, displacement, and health systems

Migration impacts every aspect of community life. It brings diversity, ideas, and ambition but also causes trauma, instability, and exclusion. Health systems face a dual

challenge. They must address immediate needs while also transforming to include those who were not originally intended to be part of the system.

Intersectionality encourages us to examine contexts more closely. For example, consider a young migrant man who might be undocumented, belonging to a racialised group, possibly living with a disability, and navigating English as a second language. Each layer influences how health systems perceive him and how he accesses care. Intersectional research shows that migrant women encounter multiple forms of discrimination when seeking health services [31]. These issues are not just quirks of individual bias; they are embedded in systemic structures.

Policies promoting 'cultural competence' often seem familiar and routine. Providers usually participate in training sessions and discuss translation services. However, changes within healthcare systems tend to progress more slowly. Evidence from Canada highlights the effectiveness of community navigator programmes, which help immigrants overcome challenges such as language barriers, health literacy gaps, and unfamiliarity with the healthcare system. By bridging these gaps, navigators offer a promising way to improve access and equity for immigrant populations [32].

Although mental health services are available, refugees frequently remain unseen within healthcare systems. These services seldom address the complex trauma caused by displacement or the underlying issues refugees face. A Canadian review illustrates how specific practices can hinder both health and access to services for newcomers, exposing systemic barriers that exclude them from planning and policy processes [33].

There are, however, promising alternatives. Cultural and health navigators, often peers from migrant communities, help bridge the gap between systems and individuals. A community-based study in New York demonstrated that peer navigators from within migrant communities significantly improved diabetes management and access to healthcare among underserved immigrant groups [34]. Another study during the pandemic praised navigators for facilitating vaccine outreach and follow-up in displaced communities [35].

Several pillars underpin these successes:

- Navigator roles are built on trust and the everyday social context.
- Systems that integrate navigator care into pathways, rather than as add-ons.
- Data systems that record migration status, language, legal status, and housing conditions.

This integration creates a virtuous cycle: systems become more responsive, migrants feel included, and trust begins to develop.

Information is power. A study of refugee-background service users in Australia revealed that clinicians often rely on informal methods such as Google Translate, community advice, and cultural impressions rather than systematic approaches that acknowledge complexity [36]. Such reliance leads to inconsistencies, confusion, and exclusion.

Ultimately, this presents both a challenge and an opportunity. Health systems that incorporate migrants perform better. They enhance engagement, reduce missed care, and foster shared responsibility. They do more than improve access; they transform systems by sharing power and promoting equity.

5. Health equity as a central pillar

Health equity is not just a secondary concern or ultimate goal; it is the essential foundation for building effective community health systems. Unfortunately, it is often viewed as a metric or an afterthought rather than integrated into care, policy, or governance design. This mindset is no longer acceptable.

Firstly, health equity cannot be separated from the structural factors shaping people's lives. Issues like poverty, racism, gender norms, migration status, and geography are concrete factors that influence access, opportunities, and risks. Addressing them requires going beyond service gaps to confront the deeper systems that produce these inequities [12, 37, 38]. It involves recognising that inequities are embedded in the system, not merely accidental or residual.

For too long, tools focused mainly on describing disparities and identifying who is left behind. Now, the focus needs to shift towards actively disrupting these disparities. The Public Health Wales Equity Toolkit, for example, extends beyond statistics to suggest local actions rooted in structural understanding, including governance changes, workforce reforms, and resource redistribution [39]. Similarly, the Centers for Medicare & Medicaid Services (CMS) Health Equity Framework outlines a 10-year plan to embed equity across the U.S. federal health system, from data architecture to payment reforms [40].

While health equity audits are common, they have limitations—they are often retrospective or compliance-driven. When done effectively, however, they can identify silent exclusions and demonstrate how system design sustains disadvantages. A digital health equity audit across U.S. platforms showed that unchecked telemedicine could worsen gaps for rural, older, or linguistically minoritised groups [41]. The solution was not to abandon digital tools but to redesign them with those users in mind.

This highlights that equity is a systems problem. Ignoring feedback loops allows inequity to persist. Disadvantage leads to poorer outcomes, eroding trust, reducing engagement, and lessening influence over harmful systems. Ending this cycle requires focus on governance, leadership, and lived experience [42]. Equity must be more than a value; it must be actively achieved.

An effective model comes from Georgetown University's Health Equity Programmes of Action framework, which outlines seven principles: empowering participation and inclusive leadership; maximising health equity; acting across health systems and beyond; ensuring marginalised groups are counted; setting clear actions, targets, and timelines; establishing accountability mechanisms; and maintaining sustained political commitment [43]. These principles translate into operational strategies focused on governance, community leadership, data-driven monitoring, and cross-sector solutions. In Camden, UK, a child health audit led to changes in housing, school meals, and perinatal care, driven by local, disaggregated, community-owned data [44].

Place is critical. Equity is not a universal solution; it must be adapted. A rural transgender male experiencing drought has different needs from an urban unemployed migrant facing air pollution and housing exclusion. Intersectional equity must be flexible, guided by local knowledge. Systems should ask: who is missing? Who is misrepresented? Who is marginalised by default practices?

Trust is essential. Without it, communities will not engage. Building trust takes time and involves showing that systems can listen, adapt, and remain accountable. Recognising community health workers, peer navigators, and interpreters as vital infrastructure is crucial. Equity must also be embedded in funding, procurement, recruitment, and data systems. Long-term relationships, beyond crises, are key.

Overall, health equity is more than a policy—it underpins every aspect of community health. As challenges like climate change, migration, and inequality grow, prioritising equity is essential and non-negotiable.

6. Towards an intersectional, systems-based approach

The convergence of climate change, displacement, gender inequity, and systemic injustice has exposed the limitations of isolated health responses. Community health systems must now evolve beyond linear or top-down models into layered, participatory structures rooted in equity. This section champions an integrated approach based on intersectional systems thinking, not as a theoretical idea but as a practical framework for transformation.

6.1 Framework proposal: the intersectional systems framework for community health

Inspired by contemporary systems theory and inclusive governance models [45], this framework shows how inclusion can be embedded across all levels of community health practice (**Figure 1**). It highlights how various interconnected factors, such as climate vulnerability, forced migration, gender norms, healthcare access, and economic exclusion, interact to create risks or build resilience. These factors are not isolated; instead, they form interconnected systems that, depending on the organisation of power, data, and leadership, can either increase exclusion or act as protective elements.

At its core, co-production emphasises a fundamental power shift, recognising communities as active participants rather than passive recipients, co-creating

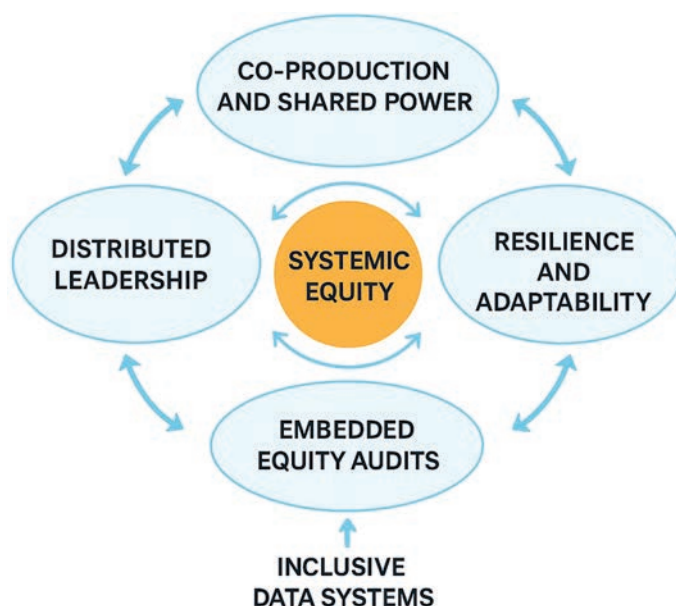


Figure 1. Intersectional, systems framework for Community Health (Diagram created by the author based on the original framework described in this chapter). This diagram presents the nested structure of intersecting influences and feedback loops across individual, community, and structural levels.

systems. Surrounding this core are data, leadership, and governance structures that must be flexible, inclusive, and reflective. Together, these layers foster a new approach to health systems that listens, adapts, and responds to complex, evolving realities.

6.2 Core principles

1. Co-production and shared power

Co-production is more than just consulting; it represents a fundamental change in how authority, knowledge, and responsibility are shared. Instead of viewing communities as mere recipients, it involves them as co-designers and co-implementers. This approach builds trust, accountability, and ensures that responses reflect lived experiences rather than assumptions. Evidence increasingly indicates that co-production boosts service uptake, reduces inefficiencies, and promotes sustainability by aligning interventions with community needs [46].

2. Distributed leadership

Traditional systems often centralise leadership, but complex public health issues demand a more flexible approach. Distributed leadership empowers those closest to the problem—local health workers, peer navigators, women leaders, indigenous knowledge holders, and frontline responders to act. This diversity enhances system responsiveness to changing threats and fosters more democratic, accountable governance [47].

3. Resilience and adaptability

Resilience involves more than bouncing back; it requires transforming systems after disruptions. Community health systems need adaptive learning cycles that enable flexible responses to climate events, migration, and political changes. This includes investing in scenario planning, real-time feedback, and inclusive contingency plans. For example, the Planetary Health Equity Hothouse project in Australia investigates how governance can be restructured to embed adaptive learning, climate-responsive planning, and health equity into transformation processes [48].

4. Embedded equity audits

Active monitoring of equity is essential, not optional. Health equity audits can reveal structural gaps and hidden exclusion patterns, especially in digital, remote, or informal systems, if designed well. They assist in resource reallocation, policymaking, and ensuring services reach at-risk populations. Audits must be conducted regularly, transparently, and participatorily to avoid becoming mere compliance exercises. When used early in programme cycles, they serve as tools for structural change, not just accountability [49].

5. Inclusive data systems

Data are not neutral; what we measure and how we interpret it reflect and reinforce power dynamics. Inclusive data systems aim to capture intersectional realities—who is missing, misrepresented, or invisible. Community-led indicators, participatory data collection, and disaggregated analytics help identify marginalisation patterns in real time, improving policy responsiveness and legitimacy. Without such systems, equity remains uncertain [50].

6.3 Practice-informed case examples

6.3.1 Case 1

Detroit Heatwaves, Housing, and Health (USA)—The Housing, Health, and Heat (HHH) Detroit initiative was created in response to the increasing frequency and intensity of urban heatwaves, especially affecting low-income communities living in poorly insulated homes [51]. Residents were trained and mobilised to collect data on indoor temperatures, health symptoms, and housing conditions. Their experiences played a key role in identifying risk hotspots and developing solutions such as cooling centres and improved housing insulation policies. This initiative exemplifies co-production and shared leadership, with residents, researchers, and city officials jointly handling data collection, understanding, and policy advocacy. It aligns with the framework's emphasis on inclusive data systems and adaptive governance that reflect community realities [52].

6.3.2 Case 2

Ahmedabad Heat Action Plan (India)—Launched in 2013, this plan is among the first large-scale, city-level heat preparedness programmes in South Asia. It was developed through collaboration among the Ahmedabad Municipal Corporation, local public health officials, and academic institutions. Key to its success was the involvement of community health workers who conducted door-to-door outreach in vulnerable slum areas, sharing multilingual information and offering guidance tailored for women, older adults, and children. The plan incorporated early warning systems, public awareness campaigns, and cross-sector capacity building. It demonstrates resilience and adaptability, showing how localised, gender-sensitive, and context-specific interventions can reduce death tolls during extreme heat. It underscores the importance of systemic integration and decentralised communication mechanisms in promoting health equity and preparedness [53].

6.3.3 Case 3

Participatory Mapping in Belo Horizonte (Brazil)—In flood-prone urban areas of Brazil, marginalised communities are often excluded from formal planning and disaster response processes. A spatial-participatory initiative involved residents directly in mapping flood risks, drainage problems, and access barriers using participatory GIS and community workshops. Combining local knowledge and lived experience with spatial data, they identified priority areas for investment and response. This approach exemplifies distributed leadership and inclusive data systems, with residents becoming co-producers of actionable knowledge rather than passive policy recipients. Incorporating lived experiences into decision-making shifted power dynamics, making governance more accountable and enabling more equitable flood risk reduction [54].

In summary, the intersectional systems framework is more than a theoretical idea. It integrates innovative practices with core principles, proposing a community health system equipped to address today's complex, climate-related, and ethical challenges. As discussed next, implementing this framework involves aligning policies, work-force and evaluation systems to promote structural equity and flexibility. A community health approach rooted in intersectionality and co-production can guide systems towards sustainability, justice, and fairer power sharing.

7. Implementation considerations

Implementing intersectional, systems-based strategies demands careful planning, sufficient resources, and ongoing learning. Innovation must be supported by strong institutional commitment and clear accountability. This section explores essential factors for successful implementation, including policy, workforce, and evaluation, and provides strategies to integrate equity and resilience into community health systems.

7.1 Policy levers: planning, funding, and governance

Effective policy design must acknowledge the realities faced by marginalised communities. Planning processes that neglect lived experiences risk perpetuating inequality. Governments and institutions should adopt participatory governance within health and climate resilience strategies, using tools like citizen juries, community panels, and local co-design workshops to enhance accountability and negotiate trade-offs [55].

Funding is one of the most influential levers, as budgets reflect priorities. Targeted investments in community co-creation, equity audits, and climate-resilient infrastructure are crucial. The UK's Core20PLUS5 approach exemplifies this by directing resources to the 20% most deprived groups, along with local groups at-risk of exclusion, such as ethnic minorities or homeless populations [56]. This approach balances national consistency with local adaptability.

Governance frameworks must evolve to handle complexity. Multisectoral coordination bodies that include health, housing, environment, and community sectors can support integrated planning and prevent fragmented efforts.

7.2 Workforce implications: training, experience, and integration

Creating an inclusive, adaptable workforce is essential for successful implementation. Frontline providers, public health officers, and planners should receive training not only in technical skills but also in structural competence, which involves understanding how social and political factors affect health [57].

Adding roles that draw on lived experience, such as community navigators, peer educators, and cultural mediators, helps build trust and effectiveness. In New Zealand, Māori health navigators have shown success in enhancing chronic disease management and access to services among indigenous communities [46, 58].

Intersectoral teams should become standard practice rather than the exception. Climate adaptation, mental health, social work, and data analytics must be integrated into primary care and public health settings. Collaboration across disciplines enables a more comprehensive and sustained response to community needs.

7.3 Evaluation challenges and opportunities

Assessing the success of intersectional models goes beyond traditional metrics. Common indicators often overlook process equity, relational trust, or system adaptability. Therefore, evaluators should use mixed methods that combine quantitative results with qualitative stories and participatory feedback. Adaptive metrics, which change based on community priorities, are especially important. For example, the SHAREdash project in the U.S. Northwest offers a community-informed health equity

dashboard co-created with rural public health professionals, using mixed methods to ensure it is relevant, usable, and trustworthy. Proper evaluation also requires dedicated investment. Funding bodies should support both intervention delivery and the learning process. Embedding evaluation teams within implementation teams can help align design with real-world conditions. Achieving change requires adaptive policies, a reoriented workforce, and evaluation approaches rooted in equity and complexity.

8. Conclusion and future directions

This chapter argues that community health cannot be improved through incremental reforms or isolated programmes alone; it requires a fundamental reimagining of community health as a systems-level, justice-driven endeavour. This approach must prioritise equity, co-production, and resilience as core principles. Given the impacts of climate change, forced migration, and deep-rooted inequalities, traditional methods are no longer enough. We need a mindset shift—seeing community health as intertwined with social justice and environmental sustainability. Moving forward, the goal is not just to prove the value of community health systems but to embed them into governance, funding, and evaluation frameworks, making them a vital part of public health infrastructure.

The crises of climate change, rapid migration, and growing health inequities demand a profound overhaul of community health strategies. Simple reforms will not suffice; transformation must be grounded in a commitment to equity, informed by lived experiences, and centred on resilience. This involves interdisciplinary collaboration, pulling insights from social sciences, environmental studies, and public health to develop holistic solutions.

This chapter advocates for a systems-based, intersectional model of community health, emphasising the importance of power relations, governance structures, and data equity. Communities are active participants, not just passive recipients, capable of co-creating solutions tailored to their specific contexts. Core principles, co production, decentralised leadership, resilience, equity audits, and inclusive data systems, provide a framework for embedding equity at every system level. These principles challenge hierarchical, top-down approaches and promote participatory, community-empowering models.

Shifting to an equitable community health model requires integrating community voices beyond mere consultation into policy making, budgeting, and strategic planning. Equity audits should guide resource distribution and priorities, rather than just serve as compliance checks. Recognising climate resilience as essential to health highlights the link between environmental and human health, requiring coordinated multisectoral efforts.

Public health leaders are crucial to this change. They must act as connectors—linking institutions and communities, data and values, risks and opportunities. Leadership involves championing policy reforms, fostering inclusive, collaborative leadership styles, and investing in developing practitioners skilled in intersectional, community-led approaches. Building leadership capacity is vital.

Looking ahead over the next decade, increasing crises will heighten stakes, but they also provide unique opportunities to reimagine systems rooted in dignity, justice, and foresight. The journey is complex and demands a shared vision, strategic coherence, and firm commitment. Key to this future is adopting intersectional equity—ensuring systems serve all communities justly—and harnessing transformative,

community-based leadership. Only through this comprehensive, deeply integrated approach can we build a resilient, equitable public health system capable of addressing future challenges.

Achieving equitable, climate-resilient community health systems will demand radical integration of lived experience, transformative leadership, and ongoing commitment to systemic change.

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Chapter 7

An Evolving Model in Community Mental Health Services in Australia through Consumer-Run Organizations

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Abstract

Historically in Australia, Drop-in Centres have been a part of the Mental Health services that came under the domain of the medical professions. Since the start of the National Mental Health Strategy in Australia in 1992, Drop-in Centres have been seen as less important as part of public and private mental health services and harder for Consumers to be able to access a safe space without being watched for symptoms, where usually, records are not kept about behaviour, only attendance. The focus in Australia has been how language has changed when discussing Consumers and Consumer involvement in service delivery and planning. The other change has been the separation of the Consumer and Carer joint approach for policy development and the development of the Peer workforce. SUPER CRO Incorporated is a small charity, and SUPER CRO is an acronym for Service User, Participating, Educating, Researching, Consumer Run Organizations. The group was initially composed of mental health consumers who had come together in 2006 as part of their involvement in treatment for a variety of mental health conditions at St Vincent's Hospital in Darlinghurst, Sydney. Members of the Group travelled to the 2010 Kansas Recovery Conference to examine the Recovery Model and were pleasantly surprised to find a whole state had embraced the Consumer-Run Organization model and were willing to share their knowledge and assist SUPER CRO to bring this model to Australia. This chapter of the book will focus on the history, development, impact, and future directions of CROs in Australia.

Keywords: lived experience, trauma informed care, right to self-determination, consumer-run organizations, peer leadership, recovery-oriented services

1. Introduction

1.1 Origins and definitions

Historically, peer-run Drop-In Centers were set up as alternatives to traditionally provided services, not as adjuncts to treatment. The classic statement of this function of the Drop In is found in Judi Chamberlin's book "On Our Own" [1]. "The original purpose of Drop-Ins was fivefold:

1. To provide a safe place where those economically disadvantaged by their mental health status can be off the street.
2. To provide a place where people with common treatment experiences can talk freely and be understood.
3. To provide grassroots gathering to address improvements that can be made in the system, to address wrongs, to have a common voice that will be given attention because it comes from the rubric of an organization.
4. To provide a place where usually a phone, bathroom, and information, sometimes food, is available.
5. To provide a place where people can be natural without being watched for symptoms, where usually records are not kept about behavior, only attendance".

Today, Consumer-operated Service Programs are part of the continuum of community mental health care in the USA. The Substance Abuse and Mental Health Service Administration (SAMSHA) Library has a lot of information to show how this has happened (see [2]).

In Phyllis Book *Fighting for Recovery, an activists History of Mental Health Reform* [3] on p 126 recalls Chamberlain and other activists dislike for the use of the term Consumer. This continues in Australia even today.

The consumer mental health movement is now 60 years old, and the term consumer and drop-ins have survived the early days of the movement when current or ex-patients might meet in someone's apartment or at a community center or in the basement of an urban church [4].

This following quote from Penney and Prescott [5] highlights some of the issues that still need to be addressed in 2025;

"A particular challenge facing psychiatric survivors is the widespread assumption of incompetence by virtue of their diagnoses. This iatrogenic vulnerability puts them at risk of losing the fundamental right to speak for themselves. Movement leaders insist that anyone who survives psychiatric treatment is uniquely qualified to speak, write and bear witness to those experiences. Increasingly, survivors have demanded a place in policy, practice and research discussions affecting their lives. Adopting a slogan of the South African disability rights movement, survivors continue to call for 'Nothing about us without us!'"

1.2 Distinctive features

Mental health Consumer-run Organizations (CROs) are a low-cost, evidence-based strategy for promoting recovery. To increase CRO utilization, characteristics that promote engagement need to be identified and encouraged.

Brown and Townley's study (for more information, see [6]) "examined individual and organizational characteristics that predict three types of engagement in CROs—attendance, leadership involvement, and socially supportive involvement. Methods: Surveys were administered to 250 CRO members attending 20 CROs. Leaders of each CRO reported organizational characteristics through a separate questionnaire. Multilevel regression models examined relationships between predictors and indicators of CRO engagement. Results: Perceived sense of community was the only characteristic that predicted attendance, leadership involvement, and socially supportive involvement ($p < .001$). Perceived organizational empowerment, shared leadership, peer counseling, and several demographic characteristics also predicted some measures of engagement. Conclusions: CROs that can effectively promote sense of community, organizational empowerment, shared leadership, and peer counseling may be better able to engage participants. The document considers several strategies to enhance these characteristics, such as collectively establishing values and practicing shared decision making".

1.3 Core values

1.3.1 Shared leadership owned, controlled and operated

Shared Leadership owned, controlled and operated in the context of consumer-run organizations (CRO), refers to a collaborative approach where leadership responsibilities and influence are distributed among multiple individuals within the organization. It's a key principle of CROs, which are owned, controlled, and operated by the individuals who use the services they provide, often in the mental health field. Shared leadership encourages team members to take responsibility for tasks and value the contributions of all members. In essence, shared leadership in a consumer-run organization emphasizes the collective strengths and experiences of its members, promoting an environment of mutual respect, support, and empowerment. It shifts from a traditional hierarchical model to a more collaborative and participatory structure where everyone has a voice and the opportunity to contribute to the organization's success [2, 7].

1.3.2 Empowerment

CROs are fundamentally structured around a set of core values [5] that distinguish them from traditional, professionally led mental health programs. At the heart of these values is *empowerment*. In these settings, individuals are not merely passive recipients of care but are recognized as experts in their own lived experiences. This model places consumers at the centre of decision-making, giving them the agency to shape services that best meet their needs. Empowerment in this context challenges traditional power hierarchies and fosters a sense of ownership over the recovery process.

1.3.3 Autonomy

Autonomy closely tied to empowerment is *autonomy*. By encouraging self-determination, consumer-run services support an environment where individuals can independently chart their paths toward recovery. Autonomy asserts that each person's journey is unique, and that the best outcomes are achieved when decisions are made by those who experience the challenges firsthand. This self-directed approach contrasts sharply with conventional models, where professionals often prescribe treatment paths without the same degree of consumer input.

1.3.4 Mutual support

Mutual support is another critical pillar of CROs. Building on the idea that shared experiences and collective wisdom are powerful tools for healing, these services foster environments where consumers support one another. Peer-led groups and networks facilitate an exchange of ideas and coping strategies that can diminish feelings of isolation, reduce stigma, and promote community resilience. The reciprocal nature of mutual support reinforces the belief that everyone has both something to gain from and something to contribute to the group.

1.3.5 Recovery orientation

Recovery orientation finally, the *recovery orientation* shifts the focus from managing symptoms to cultivating hope, resilience, and overall well-being. Rather than emphasizing deficits or illness, a recovery-oriented approach aims to build on strengths, resourcefulness, and the capacity for growth. This perspective helps individuals to envision a future beyond illness, which is a critical component in sustaining long-term recovery.

Research and policy analyses have consistently underscored that when these core values are effectively integrated into service design and delivery, there is a notable improvement in mental health outcomes, including enhanced self-esteem, increased satisfaction with services, and a greater sense of community belonging.

2. Historical context and evidence based community mental health programs

2.1 Early research

Brown and Rogers' research [8] "reviews the impact of CROs on transformative change in mental health. The research traces the history of mental health self-help and psychiatric survivor movements and shows how these led to the creation of CROs. Through hard-fought battles, CROs are now a normal part of the US mental health landscape. The chapter reviews the theoretical foundations of CROs, research on their effectiveness, and best practices for the promotion of transformative change, including the creation of empowering and socially supportive environments and policy and community change. It concludes by providing future directions for transformative change in and with CROs. CROs can serve as important complements to mainstream services or as alternative settings for those

who view mainstream services as oppressive [9]. As such, CROs can function as mediating organizations or sites of resistance from which larger social change for mental health consumers can be made”.

2.2 SAMHSA's contributions

There is plenty of evidence SAMHSA has “collaborated with federal, state, tribal, territorial, and local partners including peer specialists to develop the National Model Standards for Peer Support Certification, inclusive of substance use, mental health, and family peer certifications. These National Model Standards closely align with the needs of the behavioral health (peer) workforce, and subsequently, the over-arching goal of the national mental health strategy” [10].

2.3 Peer work leadership statement of intent

Peer work leaders from Queensland, Victoria and NSW and colleagues from the USA participated in an International Initiative for Mental Health Leadership match [11, 12], in Brisbane on 27 and 28 February 2017.

The Australian peer work leaders resolved to issue a ‘Statement of Intent’ [13] that would communicate our intention to form a national professional association for the Australian mental health consumer peer workforce. We feel that such a statement is necessary to provide the focus for national consultations to occur that will lead to the development of a peer-run organization that can support and sustain the development of the peer workforce across all sectors.

The ‘Statement of Intent’ is supported by the international peer work leaders who attended the match – Gary J Parker, Executive Director Kansas Consumer Advisory Council for Adult Mental Health and Sherry Tucker, Executive Director Georgia Mental Health Consumer Network. Both Kansas and Georgia offer certified peer specialist training, certification and support.

3. Evolution of consumer movement in mental health programs

3.1 Global milestones

3.1.1 1970s: The emergence of the movement

In the United States, the roots of the CRO movement can be traced back to the grassroots self-help and consumer advocacy movements of the 1970s. During this period, people with lived mental health experiences began to gather in small peer-led groups. These groups challenged prevailing professional hierarchies and promoted the idea that consumers could not only shape their own recovery but also redesign mental health services to be more empowering [2].

3.1.2 1980s: Formalization of consumer-run organizations

The 1980s saw the evolution of these grassroots groups into more organized structures. Early consumer-run organizations, born out of a drive for autonomy and mutual support, started to formalize their operational practices. Research and early policy documents

from this period began to document the unique benefits—such as improved self-esteem and community integration—provided by these consumer-led initiatives [7].

3.1.3 1990s: Recognition and policy engagement

By the 1990s, CROs had gained broader recognition among policymakers and mental health professionals. Formal evaluations and increased public awareness led to a more nuanced understanding of how these services contributed to rehabilitation and recovery. This era marked a turning point where consumer-run models were increasingly cited in research and integrated into mental health reform discussions (for more information – see [7]).

3.1.4 2000s and beyond: Expansion and global networking

In the new millennium, international advocacy efforts and global conferences further catalyzed the CRO movement. Consumer-run services began to spread across various regions including parts of Europe, Asia, and the Middle East. The global exchange of ideas and best practices helped emphasize the collective values of empowerment and recovery, setting the stage for more localized adaptations in other countries.

3.2 Australian milestones

3.2.1 Early 1990s: Initiation in Australia

Inspired by progressive developments abroad, Australia started to experiment with consumer-run models in the early 1990s. Initial pilot projects and community-based initiatives laid the groundwork, introducing the core tenets of consumer empowerment and peer support to local mental health services.

3.2.2 2000s: Consolidation and advocacy

During the 2000s, consumer-run organizations in Australia began to consolidate their efforts and engage more actively in policy dialogs. These organizations emerged as vital players in the mental health landscape by pushing for service reforms that aligned with recovery-oriented practices. Advocacy materials like *The Kit: The Advocacy We Choose to Do* [7] have played an influential role in articulating the principles and practical challenges of running consumer-led services, thereby reinforcing the movement's legitimacy.

3.3 Recent developments: Innovative adaptations and policy

3.3.1 Integration

More recently, models that are similar to SUPER CRO have demonstrated how the consumer-run ethos can be successfully adapted to the Australian context. Recent milestones include greater integration of consumer-run services into state and national mental health policies, alongside growing partnerships with academic and advocacy groups. These developments reflect a maturing movement that is continuously learning from international experiences while tailoring innovations to meet local needs [15].

3.3.2 Significance of these milestones

The evolution of the CRO movement—from the grassroots beginnings in the 1970s to today's integrated service models—highlights a transformative journey. Globally, milestones reflect the shift from passive receipt of care to active consumer participation and empowerment. In Australia, these milestones underscore an ongoing commitment to adapting international best practices while advocating for locally relevant reforms. This chronology not only charts historical progress but also illustrates the dynamic interplay between advocacy and practical innovation in mental health service delivery.

3.4 Policy shifts and recognition

Mental health policy reform (see [16]) globally has taken a transformative turn over the past few decades. Traditionally, mental health care was largely dominated by biomedical models and institutional care [17, 18], which often sidelined the voices of those with lived experience. However, a significant policy shift is evident as governments and international agencies now emphasize community-based, recovery-oriented frameworks that actively incorporate consumer perspectives. For example, the World Health Organization's blueprint for mental health policy and law reform calls for care systems that are rooted in human rights, autonomy, and inclusion, thereby setting a global agenda that is at the forefront of consumer-led initiatives.

In Australia, these policy shifts have been equally impactful (see [19]). National mental health strategies and reform initiatives have progressively moved away from a solely clinically driven model [20]. Rather, reform efforts now rely on various policy levers—such as regulation, financing, and community education—to foster environments that promote consumer empowerment and peer support. An analysis of policy levers used in Australia over the past two decades reveals that consumer-run services have increasingly been recognized as critical partners in delivering effective mental health care. Key policy documents and reform analyses underscore that integrating the perspectives of CROs not only improves service quality and accountability but also enhances overall consumer outcomes [21].

Advocacy and grassroots initiatives have played a pivotal role in bringing about these policy changes. Efforts encapsulated in advocacy resources like *The Kit: The Advocacy We Choose to Do* [14] illustrate how sustained public education, lobbying, and strategic partnerships have amplified the voice of mental health consumers. These advocacy campaigns have directly contributed to policy reforms by highlighting the benefits of mutual support, self-determination, and community engagement. As a result, both local and international stakeholders now increasingly view CROs as central to constructing mental health systems that are responsive, inclusive, and recovery oriented (for more information [22]).

3.5 Challenges faced

3.5.1 Peer drift

Peer Drift in a consumer-run organization, particularly within the mental health field, peer drift (also known as co-opting) refers to a deviation from the core principles and values that distinguish peer support work from traditional clinical or medical-model approaches. Essentially, peer drift occurs when a peer

professional's responsibilities or approach to support begin to shift away from their authentic, recovery-oriented role and toward a more clinical or directive style. Key Characteristics of Peer Drift:

- Shift toward a medical treatment-oriented position: This can involve focusing on symptoms and diagnoses rather than the individual's recovery journey and personal strengths.
- Encouraging adherence to advice: Instead of supporting individuals in making their own decisions, peer professionals might lean toward telling people what to do.
- Drifting into a clinical role: Peer professionals might adopt a more clinical approach or be tasked with duties better suited for clinical providers.
- Taking on a hierarchical position: The relationship may become less structured and more hierarchical, where the peer professional acts as a coach, sponsor, or counselor, rather than a peer.
- Drifting into menial tasks: Peer professionals may be assigned tasks that are not aligned with their intended peer support duties.
- Boundary issues: Lax boundaries can lead to a less structured and potentially less supportive relationship with the individual.
- Causes of Peer Drift:
 - Peer drift can be caused by various factors, including:
 - Role confusion and ambiguity: Unclear definitions of peer roles and duties can contribute to drift.
 - Marginalization of peer professionals: Non-peer colleagues or the organizational structure may marginalize peer support workers, leading them to be assigned tasks that do not align with their intended duties.
 - Feeling uneasy in the peer role: Peer professionals might transition toward more medical or clinical positions if they do not feel comfortable in their recovery-oriented role.
 - Influence of the environment: Working in a traditional behavioral health or medically-oriented setting can lead peer support workers to adopt a more clinical approach.
 - Consequences of Peer Drift:
 - Peer drift can be detrimental to the effectiveness of peer support services and can have negative consequences for both the organization and the individuals they serve, including:

- Loss of unique benefits of peer support: The deviation from peer values and standards can reduce the positive impact of peer support on individuals' recovery and well-being.
- Reduced trust in peer support: When peer support workers are perceived as adopting clinical roles, it can erode trust in their ability to provide authentic peer support.

3.5.2 Stigma and professional resistance

Stigma and Professional Resistance one of the most persistent challenges for CROs is the stigma and skepticism that exist within traditional mental health care systems. Many conventional providers are often reluctant to fully endorse peer-led initiatives because of deeply entrenched views regarding "professional expertise." This skepticism can manifest in reduced funding opportunities, limited referral networks, and an overall hesitance to integrate consumer-led services into mainstream care infrastructures (for more information – see [2]). Such resistance not only hampers acceptance but also perpetuates myths about the efficacy of services driven by lived experience.

3.5.3 Funding and sustainability issues

CROs frequently operate with constrained budgets and inconsistent financial backing. Lacking the robust funding streams available to traditional services, many consumer-run organizations must rely on short-term grants or local fundraising efforts. This financial instability presents challenges in maintaining high-quality services, scaling operations, and investing in long-term training for peer facilitators. The chronic underfunding also limits the ability of CROs to engage in continuous quality improvement, research, and evidence-based practice development (for example – see [7]).

3.5.4 Regulatory and governance barriers

Regulatory and Governance Barriers in many jurisdictions, the regulatory framework is not well adapted to the unique operational models of CROs. Ambiguous guidelines and inconsistent certification standards can create significant operational hurdles. Moreover, balancing the need for governance and accountability with the ethos of consumer empowerment is often challenging. Many CROs struggle to align their democratic, non-hierarchical structures with regulatory requirements that were designed for traditional, professionally managed service organizations [23]. Such incongruities can delay program approvals and complicate efforts to secure sustained, institutional-level support.

3.5.5 Operational and organizational challenges

Operational and Organizational Challenges internally, CROs face additional challenges in building and maintaining capacity. Many consumer-run services depend heavily on the dedication of peer facilitators who, while rich in lived experience, may not always have formal training or access to continuous professional development. High turnover, role ambiguity, and burnout among volunteer staff can undermine

service stability and quality. Moreover, as CROs expand, ensuring fidelity to the core values of empowerment and mutual support while implementing standardized practices becomes a delicate balancing act (for more information - see [7, 24]).

3.5.6 Integration with established systems

Integration with Established Systems Lastly, integrating CROs within the broader mental health ecosystem remains a complex issue. Traditional service providers and policymakers may be unfamiliar [25] with or even wary of consumer-led models. This disconnect can result in fragmented care pathways and missed opportunities for comprehensive, collaborative care. The challenge is to establish effective communication and referral networks between consumer-led initiatives and conventional services, ensuring that the unique strengths of CROs are recognized and appropriately incorporated into overall care strategies (for more information – see [2, 23]).

3.6 Rise of co-design

3.6.1 Co-design

Co-design is a collaborative process (for example, see [26]) in which service providers and users work together as equal partners to design, deliver, and improve services. Unlike traditional models, which typically maintain a clear separation between “experts” and “recipients,” co-production values the unique insights and experiences of service users. This approach not only enriches service quality but also democratizes decision-making, ensuring that outcomes are more closely aligned with the actual needs and preferences of consumers.

3.6.2 Relevance to consumer-run organizations

CROs naturally embody the principles of co-production. In these settings, consumers—those with lived experience—are entrusted with leadership roles and directly influence how services are structured and delivered. By blurring the boundaries between service provider and service user, CROs facilitate a culture of mutual accountability and innovative problem-solving. This operational model shifts the focus from a one-way provision of care to a dynamic, collaborative exchange where every participant contributes to the process [5].

3.6.3 The rise and broader recognition of co-design

The Rise and Broader Recognition of Co-design the increased prominence of co-design in public and health services can be linked to ongoing critiques of top-down, clinician-led models, which often overlook the value of experiential knowledge. Academic and policy-oriented research has underscored the benefits of adopting co-design—from enhanced consumer satisfaction to more effective and adaptable service systems. Reviews and analyses have shown that incorporating co-design into service design can lead to higher levels of engagement, improved outcomes, and greater overall service sustainability [27]. Such evidence has contributed to a broader recognition of co-design’s potential, influencing policymakers and practitioners alike to consider more inclusive, collaborative approaches.

3.6.4 Implications for future service innovations

Implications for Future Service Innovations for CROs, the rise of co-design represents both an opportunity and a guiding framework for future innovations. As consumer-led initiatives continue to evolve, adopting co-design as a core operating principle reinforces the movement's commitment to empowerment, mutual support, and recovery orientation. Moreover, by leveraging co-design, CROs can more effectively respond to emerging challenges and tailor their programs to the complex, evolving needs of the communities they serve [28, 29].

4. Where do CRO's fit In

4.1 Contextualizing CRO's and community mental health models

There is growing recognition in the fields of public health and mental health services research that the provision of clinical services to individuals is not a viable approach to meeting the mental health needs of a population. Despite enthusiasm for the notion of population-based approaches to mental health, concrete guidance about what such approaches entail is lacking, and evidence of their effectiveness has not been integrated. Drawing from research and scholarship across multiple disciplines, this review provides a concrete definition of population-based approaches to mental health, situates these approaches within their historical context in the United States, and summarizes the nature of these approaches and their evidence. These approaches span three domains: (a) social, economic, and environmental policy interventions that can be implemented by legislators and public agency directors, (b) public health practice interventions that can be implemented by public health department officials, and (c) health care system interventions that can be implemented by hospital and health care system leaders [30].

Although numerous studies have examined the effects of community-based mental health care programs in Australia, no synthesis of this literature exists. Donalds systematic review of peer-reviewed and gray literature described the types of community-based mental health care programs delivered and evaluated in Australia in the past 20 years and evaluated their impact in improving outcomes for those with a serious mental illness (SMI) [31].

4.2 Positioning CROs

The following information is taken from an article by Schell [4]. "Their research supports consumer-run services as valuable and effective. Drop-ins have the lowest threshold for participation in all consumer-run programs. There is no triage to belong to. Treatment is conversation or respect for someone who seeks silence. Participants are not required to show up at a particular time or to read classroom material. One is not considered a failure if he/she gets a cup of coffee and sits in a chair or goes to sleep on the couch. It's okay to draw or sing all day. It's okay to play games on the computer. It's okay to do absolutely nothing but think and decide what you want to do later. On the other hand, drop-ins offer the greatest opportunity for volunteer and paid work and skill development from payroll to driving to reception to arranging furniture."

5. Case study: SUPER CRO

The start-up charity SUPERCRO Incorporated [15] is being used as an example to highlight its development in Australia as it begins to take the necessary steps to grow. Varga [32] describes it as “*a very small enterprise*.” Members describe it as an organization without walls.

The foundational members of SUPER CRO initially were composed of mental health consumers who had come together in 2006 as part of their involvement in treatment for a variety of mental health conditions at St Vincent’s Hospital in Darlinghurst, Sydney. They came together on a Wednesday afternoon as the SUPER Group. SUPER is an acronym for Service Users, Participating, Educating and Researching. In 2010, two of the SUPER Groups members were supported to attend the Recovery Conference in Wichita, Kansas to observe and report back to St Vincents what was involved in becoming an effective consumer-run organization based on the model that has been running successfully in the United States since 1985 [4].

This research was conducted by COSP- Multisite Study, FliCA site, SAMHSA in 2003 and showed that “Unlike any service that makes up mental health services, a drop-in center is distinguished by the fact that it is not prescribed for anyone by anyone. Clients self-select to attend, and this step is an act of self-determination that accounts for the value of the enterprise.” SUPERCRO Incorporated’s overarching and audacious goal is to demonstrate that this model can work in Australia.

In 1991, The Australian Government gave people with a mental health condition the Statement of Rights and Responsibility [33] to be involved in the National Mental Health Strategy a 20-year plan to reform mental health services across Australia. Holmes said, [34] “seeking the views of consumers on their perceptions and experiences of public and private mental health services is vital to making those services more effective, responsive and for achieving positive mental health outcomes.”

In 2016, the group created a strategic plan [35] with assistance from Gary Parker from Wichita, Kansas. In 2023, 14 of the original foundational members received the news from The Australian Charities and Not-for-profits Commission (ACNC) that it is now a Health Promotion Charity endorsed to access the following tax concessions: GST Concessions, Income Tax Exemption, FBT Exemption, and is endorsed as a Deductible Gift Recipient. The main objective for SUPER CRO’s members is to determine whether it is meeting its legal obligations and to put forward recommendations on how to manage any risks, such as cyber security attacks, and using existing resources.

In May 2025 the organization has 19 active members, as Varga ([32], p. 215) said, “*While it is possible to set up a business in a short time, a big question is how to run it successfully and profitably in the longer term*”. The group has regular Zoom monthly meetings with an agenda and notes from previous meetings. Members have been following the information from the ACNC website [36] on how to set up and run a charity.

SUPERCRO Incorporated has made a start on developing several policies, including the Code of Conduct, Privacy policy, and Conflict of Interest, as these were necessary to obtain authorisation from the ACNC to gain charity status. These members will focus on identifying additional policies so that the organization can move to the next stage of its development, and the members can be confident in SUPERCRO Incorporated’s longevity.

The organization will table its first annual report in December 2025, this report will raise awareness of the issues that McRoberts reports, ([37], p. 8), “*One of the most significant issues emerging from the establishment of the Australian Charities and*

Not-for-Profits Commission (ACNC) has been the introduction of graduated reporting requirements for charities". The current Authorized Representatives of the charity are realizing that to meet the minimal requirements and to move to a Micro Enterprise, as Varga describes [32] in his article, will lead to changes that some members did not realize would be necessary when they signed up as members of the organization.

Armstrong [38] reported in 2015 "studies suggests that a more judicious approach to treating mental disorders would be to replace a "disability" or "illness" paradigm with a "diversity" perspective that considers both strengths and weaknesses and the idea that variation can be positive in and of itself. To this end, a new term has arisen within the autism rights community: neurodiversity."

Unlike CRO's in USA that are recognised and funded as part of the mental health system in many of the states and territories [2] except for several small grants the majority of SUPER CRO's programs and initiatives have been funded and supported by its members to build up awareness and recognition of CRO's as a model that can be supported in Australia. Our website has a range of projects and products that members of SUPER CRO have created to support SUPER CRO to become an independent consumer-led and run entity to achieve its mission.

6. Challenges and sustainability

6.1 Funding and resource access

Consumer-run organizations (CROs) in Australia face considerable challenges in establishing financial sustainability. Unlike traditional mental health services that typically secure long-term funding from established government and private sources, many CROs operate on precarious, short-term grants, philanthropic donations, and ad hoc community fundraising efforts. This funding volatility restricts the ability to plan long-term programming, invest in critical infrastructure, or provide consistent training for peer facilitators, thereby affecting the overall stability and growth of these consumer-led initiatives [21].

In Australia's competitive funding environment, traditional service providers often benefit from well-established administrative systems and historical funding relationships. As a result, CROs—whose governance is usually more democratic and reliant on volunteer contributions—are at a disadvantage when competing for conventional funding streams. To address this gap, many CROs have started exploring alternative funding avenues such as social enterprise initiatives, collaborative partnerships with local government, and innovative crowdfunding strategies. These alternative models not only provide much-needed supplemental revenue but also help diversify the funding base, reducing the risk associated with reliance on any single funding source [7].

Moreover, recent policy reforms have begun to recognize the unique value of consumer-led services in achieving a recovery-oriented mental health system. Australian government and policy reviews are increasingly advocating for funding mechanisms that support community-based and consumer-run models. However, even with this policy shift, CROs often encounter funding challenges due to stringent eligibility criteria, administrative burdens, and the need to conform to traditional reporting structures. This mismatch between the flexible, grassroots ethos of CROs and the standardized demands of funding agencies remains one of the key obstacles to securing sustainable, long-term financial support [19].

Addressing these challenges requires coordinated efforts among policymakers, CROs, and funding bodies to design more flexible funding models. Capacity-building initiatives streamlined administrative processes, and strategic partnerships that leverage both public and private investment are critical steps toward creating a secure financial foundation. Establishing such a foundation will enable CROs to retain their innovative, consumer-led approaches, ultimately contributing to a more diverse and resilient mental health service system in Australia.

6.2 Navigating power imbalances

One of the significant challenges that CROs face is engaging with traditional, hierarchical service providers while protecting the very principles—empowerment, autonomy, and co-production—that define their identity. Mainstream mental health settings are often structured around top-down decision making, which can sometimes undermine the consumer-led ethos that CROs aim to preserve. To counter this, several strategies have been developed and implemented.

6.2.1 Establishing clear boundaries and role definitions

A foundation for equitable collaboration requires formalizing roles through mechanisms like memoranda of understanding (MOUs) or partnership agreements [39]. These documents can clearly delineate decision-making powers and responsibilities, ensuring that consumer voices are not diluted. Formal agreements help to set expectations and reinforce that CROs retain their autonomy even as they contribute to broader service frameworks.

6.2.2 Emphasizing co-design as a collaborative model

Co-design facilitates a more balanced power dynamic by integrating consumers as equal partners in service design and delivery. Through structured frameworks that promote shared decision making, CROs and mainstream providers can create joint governance models. In this setup, both groups contribute expertise—professionals bring clinical insights while consumers contribute essential lived experiences—resulting in a partnership that is less hierarchical and more mutually accountable [27].

6.2.3 Building capacity through training and empowerment workshops

To better equip consumer representatives for collaborative engagements, dedicated training on power dynamics, implicit bias, and negotiation techniques can be invaluable. Such capacity-building initiatives not only reinforce the confidence of CRO members but also provide them with the skills needed to assert their perspectives effectively during inter-organizational meetings. This approach helps to level the playing field and reduce the risk of dominance by established service providers [40].

6.2.4 Utilizing independent facilitation or mediation

Occasionally, a neutral mediator can be instrumental in ensuring balanced participation during collaborative efforts. An independent facilitator can oversee meetings, manage disagreements, and make sure that all voices are heard without

compromising the autonomy of the CRO. This method of conflict resolution can preemptively address potential power conflicts before they escalate, thereby preserving the integrity of consumer-led input [2].

Collectively, these strategies help CROs navigate the inherent power imbalances when interfacing with mainstream services. By enforcing clear guidelines, embracing co-production, investing in training, and occasionally relying on neutral facilitation, CROs can maintain their core values and continue to drive innovative, recovery-oriented practices even within larger, more hierarchical systems.

6.3 Capacity building and burnout

CROs often operate within resource-constrained environments where staff and volunteer burnout are a significant risk. Effective capacity building and robust staff development initiatives are critical not only for individual well-being but also for sustaining organizational resilience and long-term service quality.

6.3.1 Capacity building and staff development

Capacity Building and Staff Development for CROs, capacity building involves creating opportunities for professional development, mentoring, and skill-sharing among staff and volunteers. Regular training sessions, workshops on effective service delivery, and peer-supervision models can enhance the skills needed to navigate complex organizational challenges. These approaches not only empower staff to deliver high-quality, recovery-oriented services but also promote a culture of continuous learning—essential in environments where resources may be limited. For example, peer-led training and collaborative problem-solving sessions are instrumental in reinforcing a shared vision and ensuring that the principles of consumer autonomy and mutual support remain central to service delivery [41].

6.3.2 Burnout prevention strategies

The emotionally demanding nature of delivering mental health services means that burnout is a constant threat. Burnout among staff is characterized by chronic physical and emotional exhaustion, cynicism toward one's work, and reduced professional efficacy. To mitigate these risks, CROs have adopted several strategies:

6.3.3 Structured work processes

Implementing clear work schedules and realistic caseloads can prevent overextension.

6.3.4 Wellness programs

Initiatives such as mindfulness training, stress-management workshops, and resilience-building practices help individuals develop personal recovery routines that complement organizational safety nets.

6.3.5 Access to support networks

Continuous access to mentoring, peer support groups, and external counseling services ensure that employees do not face challenges in isolation [42].

6.3.6 Ensuring organizational resilience

Ensuring Organizational Resilience Organizational resilience is achieved when there is a robust interplay between capacity building and burnout prevention. By developing training programs that incorporate stress-management techniques and by establishing flexible staffing models, CROs can remain agile in the face of evolving service demands. Regular evaluation of staff workload, the incorporation of feedback mechanisms, and the nurturing of leadership skills within the team all contribute to a resilient organization. Such practices not only mitigate the risk of burnout but also ensure that the organization remains adaptive, sustainable, and true to its consumer-led ethos even when faced with transient funding or operational challenges [43].

Together, these components form the backbone of an enduring consumer-run organization structure—one that prioritizes staff well-being and, by extension, enhances service delivery. When CROs invest in such comprehensive capacity building and burnout prevention strategies, they not only boost individual resilience but also secure the organizational strength necessary to drive long-term community impact.

6.4 Succession planning

Effective succession planning is critical to the long-term stability and vitality of consumer-run organizations (CROs). In these organizations, which are founded on principles of empowerment, mutual support, and recovery orientation, leadership transitions must be managed carefully to preserve not only institutional memory but also the unique consumer-led culture that defines them. Abrupt gaps or poorly managed transitions can undermine trust, disrupt service continuity, and erode the foundational ethos that drives these organizations.

Evidence from SAMHSA supports the notion that continuity in leadership is a key element of successful CROs. In its report, *Consumer-Operated Services: The Evidence*, SAMHSA emphasizes that robust internal governance—of which succession planning is a central component—is essential to achieving positive service outcomes and maintaining the integrity of consumer-led practices [2]. By preparing emerging leaders through formal mentoring, training, and structured internal processes, CROs can better ensure that the wealth of experiential knowledge and the consumer-focused approach are transmitted without dilution during leadership transitions.

A proactive succession planning strategy typically involves several core components:

6.4.1 Structured mentoring and training programs

These initiatives help cultivate leadership skills among consumers by pairing emerging leaders with experienced mentors and providing targeted training in areas such as strategic planning, governance, and stakeholder engagement.

6.4.2 Formalized leadership transition processes

Establishing clear policies, role definitions, and protocols for transferring responsibilities ensures that organizational momentum is not lost during leadership changes.

6.4.3 Inclusive decision-making models

Incorporating co-production principles into the leadership transition process ensures that all voices are represented, reinforcing the democratic, peer-led nature of CROs.

By integrating these approaches, CROs can minimize disruptions during leadership changes, thereby sustaining their organizational momentum and reinforcing the stability necessary for long-term impact. In essence, effective succession planning enables consumer-run organizations not only to survive periods of leadership change but also to thrive by continually renewing their commitment to consumer empowerment and recovery-oriented service delivery.

7. Policy and advocacy perspectives

7.1 Influencing systems change

CROs have rapidly evolved from grassroots initiatives into influential agents in driving mental health reform [7]. By centering on peer support, empowerment, and recovery-oriented practices, CROs challenge traditional, top-down service models and help reshape mental health systems toward more inclusive and person-centred care [40].

7.1.1 Catalysts for reform

One of the most significant impacts of CROs is the way they redefine service delivery. By actively involving consumers in the design, implementation, and evaluation of services, CROs help ensure that mental health systems are aligned with the needs of those who use them. Evidence from the SAMHSA report, *Consumer-Operated Services: The Evidence*, highlights that consumer-led initiatives not only improve individual outcomes but also foster more responsive and innovative mental health service ecosystems [2]. This consumer-empowerment model has been identified as a key catalyst in moving from traditional, clinician-dominated frameworks toward recovery-oriented systems. Hopefully CRO's will be considered as part of the reform package for the unmet need outside the National Disability Insurance Scheme [25].

7.1.2 Bridging gaps between policy and practice

CROs play a vital role in bridging the gap between policy intent and clinical practice. Their advocacy efforts and operational successes have informed policy reforms that increasingly emphasize community-based and recovery-focused care. For instance, SAMHSA's expert panel on "Operationalizing Recovery-Oriented Systems" provides a framework that underscores the importance of integrating consumer-led components into broader mental health strategies [44]. By highlighting successful outcomes and demonstrating the feasibility of alternative models, CROs provide policymakers with evidence-based examples that support legislative, and funding reforms aimed at decentralizing mental health care and reducing reliance on institutional settings.

7.1.3 Influence on systemic structures

The influence of CROs extends beyond service delivery to the very structure of mental health systems. CRO-led initiatives have been instrumental in advocating for inclusive governance and participatory decision-making, which are now increasingly recognized as essential for sustainable reform. Integrating peer support roles and co-production principles into service models not only improves accountability but also helps to dismantle entrenched power imbalances in mental health care. In this way, CROs contribute to a broader shift in systems thinking—from one that is predominantly hierarchical to one that values shared leadership and collaborative problem-solving.

7.1.4 Driving change through lived experience

Fundamentally, CROs leverage the power of lived experience to drive systemic change. The firsthand insights of mental health consumers provide a credible basis for challenging outdated service paradigms and promoting practices that are truly recovery oriented. This grassroots input has influenced policy shifts at both local and international levels. As CROs continue to demonstrate their effectiveness, they increasingly serve as models for integrated, person-centred service delivery that is adaptable across various cultural and systemic contexts.

7.2 Lived experience in policymaking

7.2.1 Incorporating lived experience into policy design

Incorporating Lived Experience into Policy Design modern mental health reform increasingly recognizes that policies are most effective when they are grounded in the realities of those most affected by them. Individuals with lived experience—those who have navigated mental health challenges firsthand—offer unique insights that enrich policymaking. Their contributions have been pivotal in shifting mental health strategies from a solely clinical, top-down model to one that is collaborative and recovery oriented. This shift is evidenced by the widespread integration of consumer-run organizations (CROs) into service frameworks, ensuring that policies reflect both the challenges and the resilience inherent in lived experience.

7.2.2 Evidence from the SAMHSA library

SAMHSA has long underscored the value of consumer-operated services. In its comprehensive report, *Consumer-Operated Services: The Evidence*, presents data demonstrating that services led by those with lived experience deliver improved recovery outcomes and higher consumer satisfaction [2]. This body of evidence has been influential in advocating for policies that not only acknowledge but also actively integrate the expertise that consumers bring to the table.

7.2.3 Shaping comprehensive mental health strategies

Shaping Comprehensive Mental Health Strategies, the inclusion of lived experience in policymaking has required the development of frameworks that empower individuals to participate meaningfully in decision-making processes. For example,

initiatives such as the Lived Experience Governance Framework champion a model where decision-making is shared, ensuring that policies are reflective of real-world needs while maintaining a strong human rights orientation [45]. Such models promote co-production, wherein service users and professionals work side-by-side, thereby reducing traditional power imbalances and fostering innovative, community-responsive mental health strategies.

7.2.4 Broadening the impact of CROs

Broadening the Impact of CROs When policymakers integrate lived experience into the fabric of mental health policy, it paves the way for CROs to be recognized as essential components of the service mix. Academic discussions, such as those found in recent studies published in global mental health forums, emphasize that the practical wisdom of lived experience contributes to policy robustness. These accounts stress that the partnership between consumers and traditional providers leads to policies that are more holistic, inclusive, and adaptive to community needs [46]. Ultimately, this approach results in a health system that is better positioned to deliver recovery-focused care and reduce the systemic stigma often associated with mental health challenges.

7.3 Recommendations

Embedding CROs within national mental health strategies requires a multifaceted approach that aligns policy, practice, and resource allocation with the core principles of consumer empowerment and recovery orientation. Based on evidence from the SAMHSA report [2] and related research [47], the following recommendations can guide stakeholders in effectively integrating CROs into broader mental health frameworks:

7.3.1 Formalize representation in policy and governance

National mental health strategies should explicitly recognize and incorporate consumer-run organizations by including them as key partners in policy advisory committees and decision-making bodies. Establishing formal roles for CRO representatives ensures that the lived experience of mental health service users informs policy development from conception to implementation. Evidence from SAMHSA highlights how consumer-led models drive improvements in recovery outcomes, underscoring the need for their active participation at the highest levels of mental health governance [2].

7.3.2 Develop dedicated funding mechanisms

To safeguard the financial sustainability of CROs and support their growth as innovators in service delivery, governments should create funding streams that are specifically allocated for consumer-led initiatives. This includes revising grant criteria to value peer support and co-production models and aligning funding cycles with the flexible, community-based approach of CROs. Incorporating these funding mechanisms into national mental health strategies can help to reduce the competitive pressures that often marginalize consumer-run initiatives in traditional funding environments [2, 7].

7.3.3 Institutionalize co-production and collaborative partnerships

Embedding CROs requires fostering environments where co-production is the norm. Establishing collaborative frameworks that unite conventional mental health providers with CROs can help balance expertise with lived experience. These partnerships should be underpinned by clear roles, shared governance arrangements, and mutual accountability. By routinely integrating consumer-led inputs into service design and evaluation, policymakers can ensure mental health reforms remain responsive to community needs [2, 7].

7.3.4 Enhance capacity building and evaluation frameworks

The integration of CROs must be complemented by strategies that build organizational capacity and evaluate performance using consumer-centred metrics. National strategies should support training programs aimed at developing leadership and management skills among CRO staff, as well as implementing performance indicators that capture the unique contributions of consumer-led services. Establishing robust evaluation frameworks will not only drive continuous improvement within CROs but also provide compelling data to inform ongoing policy development [2].

7.3.5 Facilitate knowledge exchange and research partnerships

To further legitimize and refine the integration of CROs, national strategies should encourage collaborative research initiatives that document best practices, success stories, and challenges faced by consumer-run models. Creating national forums for knowledge exchange between CROs, academic institutions, and government agencies can promote innovations in service delivery and stimulate evidence-based advocacy. Drawn from the SAMHSA evidence base, such initiatives affirm the value of consumer-led care as a transformative element of mental health reform [2].

By advancing these recommendations, stakeholders can help ensure that consumer-run organizations are not peripheral add-ons but are central to a dynamic, responsive, and recovery-oriented national mental health system.

8. Future directions

8.1 Innovations in consumer-led models

8.1.1 Digital transformation and mobile health

CROs are increasingly embracing digital platforms to extend their reach and improve service quality. Mobile applications and online portals now allow consumers to engage in peer support, access self-management resources, and participate in virtual support groups from anywhere. This digital shift not only enhances service accessibility but also helps overcome geographic limitations. For instance, telehealth platforms and dedicated mobile apps enable real-time communication and personalized interventions, making it easier for CROs to deliver recovery-oriented services while maintaining a consumer-led ethos [48].

8.1.2 AI, data analytics, and personalized support

AI, Data Analytics, and Personalized Support Emerging practices in artificial intelligence (AI) and data analytics are further transforming consumer-led models by offering predictive insights and personalized support. CROs are leveraging machine learning algorithms and AI-powered chatbots to interpret user-generated data, tailor interventions, and monitor mental health indicators continuously. These tools help create data-driven feedback loops that improve service responsiveness and effectiveness. By integrating these technologies with traditional peer support, CROs can offer both personalized care and scalable community support—enhancing overall outcomes for mental health service users [49].

8.1.3 Collaborative digital ecosystems and secure data management

In addition to direct interventions, digital ecosystems are fostering collaboration among diverse stakeholders. Platforms that integrate blockchain technology, for example, offer secure systems for maintaining sensitive consumer data and ensuring traceability in service delivery. Such innovations support co-production models where consumers, clinicians, and administrators can share information securely, collaborate in decision-making, and contribute to continuous service improvement. These decentralized and transparent systems help democratize mental health care by reinforcing consumer autonomy and protecting privacy [7].

8.1.4 Supporting a new era of consumer-led practices

The convergence of these emerging technologies is redefining what is possible in consumer-led mental health services. Innovations are not limited to technological tools alone but extend to the development of new service delivery frameworks—such as virtual communities, online training and capacity-building platforms, and integrated feedback systems—which empower consumers in unprecedented ways. In doing so, they significantly enhance the scalability, responsiveness, and resilience of CROs. By harnessing these digital advances, CROs can continue to evolve into more agile, data-informed, and community-responsive organizations that stand at the forefront of modern mental health reform.

8.2 Scaling and replication

In 2015, SAMHSA led an effort to identify the critical knowledge, skills, and abilities (leading to Core Competencies) needed by anyone who provides peer support services to people with or in recovery from a mental health or substance use condition. SAMHSA—via its Bringing Recovery Supports to Scale Technical Assistance Center Strategy (BRSS TACS) project—convened diverse stakeholders from the mental health consumer and substance use disorder recovery movements to achieve this goal. SAMHSA, in conjunction with subject matter experts, conducted research to identify Core Competencies for peer workers in behavioral health. SAMHSA later posted the draft competencies developed with these stakeholders online for comment [41].

8.3 Integration into health systems

CROs have demonstrated significant potential to complement traditional mental health services by fostering peer support, empowerment, and recovery orientation.

To ensure these benefits are realized on a systemic level, it is essential to adopt strategies that integrate CROs within existing community mental health frameworks. The following approaches—supported by evidence from the SAMHSA library and additional research—offer a roadmap for achieving such integration.

8.3.1 Formal collaborative structures and partnership agreements

Formal Collaborative Structures and Partnership Agreements a foundational strategy is the establishment of formalized collaborative structures between CROs and main-stream service providers. This can be achieved through memoranda of understanding (MOUs) and joint governance committees that clearly define roles, responsibilities, and decision-making processes. Such formal agreements help overcome traditional power imbalances and ensure that both consumer-led initiatives and conventional clinical services work synergistically. Evidence from the SAMHSA report on consumer-operated services underscores the benefits of structured collaboration in enhancing recovery outcomes and system responsiveness [2].

8.3.2 Co-location and integrated service delivery

Co-location and Integrated Service Delivery integrating CROs into health systems can be further supported by co-location strategies. By situating CROs alongside primary care clinics, outpatient mental health centres, or community health hubs, service users benefit from streamlined access to both peer support and professional care. This model not only promotes continuity of care but also facilitates the development of multidisciplinary teams where consumer insights inform clinical practices. Research into integrated mental health models highlights that co-location can reduce fragmentation of services and improve overall mental health outcomes [49].

8.3.3 Inclusion in policy formulation and decision-making

Inclusion in Policy Formulation and Decision-Making for sustainable integration, it is critical that CROs are represented in policy development and strategic planning at local and national levels. Including consumer representatives on mental health advisory boards and within governing bodies ensures that lived experience directly influences service design and resource allocation. Such inclusive governance models have been associated with higher levels of consumer satisfaction and improved system accountability, as noted in studies evaluating the impact of peer-led initiatives on mental health reform [7].

8.3.4 Capacity building and collaborative training initiatives

Capacity Building and Collaborative Training Initiatives to support effective integration, ongoing capacity building is essential. Joint training programs that bring together CRO staff, clinical personnel, and administrative leaders can promote mutual understanding and strengthen collaborative practices. These programs may focus on shared governance, quality improvement, and culturally responsive care. By investing in capacity building, organizations reinforce the legitimacy of the consumer-led model and create opportunities for innovation in service delivery.

8.3.5 Development of coordinated funding mechanisms

Development of Coordinated Funding Mechanisms securing sustainable funding is a perennial challenge for CROs. Policymakers and funding bodies should consider creating dedicated financial streams that align with integrated community care models. Coordinated funding mechanisms that link public and private investments can help bridge the resource gap often experienced by consumer-led organizations. Such financial strategies not only facilitate integration but also empower CROs to innovate and expand their services.

Through these strategies—formal partnerships, co-location, inclusive governance, capacity building, and coordinated funding—CROs can be positioned as essential components of community mental health services. This integrated approach supports a more holistic, accessible, and recovery-oriented mental health system that leverages the unique strengths of consumer leadership.

9. Discussion

9.1 Reaffirming CROs' importance

CRO's stand apart by centering mental health reform on the strengths and realities of those with lived experience. Unlike traditional service models that often emphasize clinical expertise and top-down approaches, CROs leverage peer support, collaborative governance, and firsthand insights to drive more inclusive and effective care.

Empowerment and Peer-Led Engagement at the core of CROs is the principle of empowerment. By positioning consumers as active decision-makers rather than passive recipients of care, these organizations foster an environment where personal recovery is both the goal and the mechanism for change. The peer-led nature of CROs not only improves service accessibility and satisfaction but also challenges longstanding power imbalances in mental health care delivery [2]. This empowerment leads to enhanced self-determination and fosters recovery processes that are tailored to individual needs.

Redefining Service Delivery and System Responsiveness CROs have significantly contributed to reframing mental health services from a predominantly clinical model to one that values recovery orientation and community support. By integrating lived experience into service design and evaluation, CROs provide innovative models that are more responsive and adaptive to diverse user needs. Their approaches have informed policy reforms by demonstrating that consumer-led services can drive better recovery outcomes, resulting in a more holistic mental health system [2, 7]. Through co-production models, CROs facilitate a two-way exchange of information between service users and professionals, thereby creating more balanced, accountable, and effective systems of care.

Catalyst for broader policy change and cultural shift beyond transforming service delivery, CROs serve as catalysts for a broader cultural and policy shift in mental health reform. Their successes have underscored the value of integrating consumer voices in policymaking, promoting initiatives designed to decentralize decision-making and enhance accountability. This shift has contributed to the establishment of policies that are better aligned with the real-world experiences of those who use mental health services, thereby leading to systemic changes that support sustainable recovery-oriented care[7].

Evidence-based impact and ongoing innovation the effectiveness of CROs is further validated by studies showing improved clinical and social outcomes compared to traditional models. For example, evidence compiled in SAMHSA's report, *Consumer-Operated Services: The Evidence*, indicates that consumer-run approaches generate substantial benefits in self-esteem, community integration, and overall recovery [2]. This growing evidence base continues to inspire new innovations in service design, financing, and collaborative research, steadily solidifying the role of CROs as indispensable components of modern mental health systems.

9.2 Call to action

CROs have emerged as vital agents in reshaping mental health care by centering peer support, lived experience, and recovery-oriented practices. The evidence compiled in the SAMHSA report demonstrates that CROs deliver enhanced recovery outcomes, greater service satisfaction, and improved community integration [2]. Despite these positive outcomes, CROs often face challenges related to funding, integration, and organizational capacity that limit their full impact.

To harness the transformative potential of CROs, it is crucial that stakeholders—ranging from policymakers and funding agencies to community organizations and academic institutions—extend their support through the following actions:

9.2.1 Embed CROs in National Health Strategies

National mental health frameworks must recognize CROs as essential contributors to service delivery. This involves formalizing their role in policy advisory boards and decision-making bodies to ensure that consumer perspectives influence the design and implementation of mental health reforms [7, 47].

9.2.2 Develop sustainable funding mechanisms

Creating targeted funding streams is essential for the long-term viability and growth of CROs. By establishing flexible investment models that appreciate the unique benefits of consumer-led services, funding bodies can help CROs scale operations, invest in capacity building, and innovate continuously. In doing so, the financial sustainability of CROs will reinforce a broader shift toward recovery- and community-focused mental health care [2, 7, 19].

9.2.3 Strengthen research and knowledge exchange

Encouraging collaborative research partnerships among CROs, academic institutions, and traditional mental health providers will further substantiate the evidence base for consumer-led care. Regular dissemination of best practices and outcomes through national forums can facilitate knowledge exchange and foster innovation across service models.

9.2.4 Promote collaborative governance and capacity building

Empowering CROs through structured capacity building—such as mentorship programs and joint training initiatives—ensures that they are well positioned to maintain their consumer-led ethos even within integrated service frameworks.

This approach not only bolsters service quality but also bridges gaps between diverse mental health service models.

By taking these steps, stakeholders will not only invest in the sustainability and expansion of CROs but also contribute to a more inclusive, innovative, and recovery-oriented mental health service ecosystem. The time is ripe for decision-makers to recognize and endorse the unique contributions of consumer-run organizations as cornerstones in the future of mental health reform.

10. Conclusion

This chapter has explored the transformative impact of consumer-run organizations on mental health reform. The discussion highlighted the evolution of CROs—from grassroots initiatives that emerged out of the self-help and recovery movements to sophisticated models that are informing contemporary mental health policy. By integrating core values such as empowerment, autonomy, mutual support, and a deep commitment to recovery orientation, CROs challenge traditional, clinician-driven service models and foster environments where lived experience is valued as a vital source of wisdom.

We examined international and Australian milestones that chart the growth of the consumer-led movement, illustrating how shifts in policy and practice have recognized the importance of consumer engagement in modern mental health services. The chapter also addressed the hurdles that CROs face—ranging from funding instability and regulatory challenges to internal capacity issues—while offering strategies to mitigate these obstacles through co-production, enhanced collaboration with traditional services, capacity building, and succession planning.

Emerging innovations, including digital transformation and data-driven personalized care, are positioning CROs at the forefront of mental health service innovation. Moreover, the integration of CROs into broader health systems and the call for a collaborative, investment-driven approach underscores the ongoing evolution of mental health care toward a model that privileges inclusivity, recovery, and consumer empowerment.

In summary, consumer-run organizations not only provide an essential complement to conventional mental health services but also serve as catalysts for systemic change. Their unique contributions—rooted in lived experience and democratic participation—offer a compelling vision for a future where mental health care is more responsive, equitable, and sustainable. By embracing these innovative models and supporting their growth, stakeholders can help create a mental health system that truly reflects the needs and aspirations of the communities it serves.

Conflict of interest

The authors declare no conflict of interest.

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Section 3

Community Health Models in Diverse Settings

Chapter 8

Patient Education Barriers: Reflections and Experiences of Primary Healthcare Nurses in Abu Dhabi

Thifhelimbilu Irene Ramavhoya, Mampheko Doricah Peu and Bassam Ibrahim Alayed

Abstract

Despite the strong progress of the United Arab Emirates towards reducing chronic illnesses and overall good management of healthcare facilities, patient education programmes were found to be lacking in their effectiveness. As such, barriers to Patient education programmes in Abu Dhabi, as experienced and perceived by registered nurses working in primary healthcare settings, were explored. The study was conducted in Ambulatory Health Services primary healthcare settings in Abu Dhabi. A qualitative, explorative, and descriptive design was employed in this study. This study's participants were chosen *via* non-probability purposive sampling. Data were gathered through semi-structured focus group discussions. Five Focus Group discussions were conducted, with each group including six to nine Registered Nurses who worked as general nurses in primary healthcare clinics in different regions of Abu Dhabi. In total, 36 Registered Nurses participated in the focus group discussions. A pre-developed list of questions was used to interview the respondents. The data gathered was analysed through thematic analysis, and measures to ensure trustworthiness were followed. The data led to the identification of three barriers of patient education, namely barriers related to patients, barriers related to nurses and barriers related to the physical environment. Patients' negative attitude towards patient education, language barriers and lack of appropriate facilities had a negative impact in their education. Barriers identified can be addressed by policymakers to enhance the effectiveness of PE programmes in Abu Dhabi.

Keywords: barriers, patient education, primary healthcare, programmes, primary healthcare nurses

1. Introduction

Patient education remained an important role among health professionals. It is part of health promotion and disease prevention. Without regular patient education,

the receiver of such care finds themselves in a difficult situation. Several patients have a desire to be given health education, while others stated that patient education brings a delay at health facilities. Researchers revealed that a significant number of patients remain unaware of the ways to manage their health [1]. Moreover, lack of comprehension is also noted in patients along with difficulty remembering medical information [2]. Nantsupawat et al. [3] further confirmed limited health literacy in people. All these issues result in poor health outcomes in patients as well as increased health system costs and usage [4]. These challenges are argued to be managed through patient education which involves providing verbal instructions and information to patients, enabling them to understand their health issues and how these can be prevented and managed [5].

The American Nursing Association outlined that educating patients is a huge part of nursing practice [6–8]. PE has gained wider attention as health institutions are progressively recognising the need for patient self-management and have attempted to adopt a patient-centred approach in healthcare administration [9]. PE programmes are intended to further develop patients' self-care competencies, ultimately expanding their insight, in the prevention of disease conditions, their management, and adherence to treatment after consultations with primary healthcare nurses (PHcNs) [6].

At present, the PE programmes are encountering numerous difficulties due to various aspects such as an ageing population and changing expectations of patients and their desire to be involved in their treatment plan [10, 11]. These variables have expanded the job responsibilities of PHcNs in enhancing patients' information and comprehension of their well-being condition(s) through instructing them effectively [12–14]. PE has additionally been affected by the way that most countries, including the United Arab Emirates (UAE), are confronting increased demands for healthcare and inflating costs [15]. PE is considered as the mainstream strategy for preventing and managing these diseases. Offering appropriate education to the patients in managing their lifestyles as well as a treatment plan enhances patient outcomes [16, 17]. Even though PE is a vital part of everyday nursing practice, there are various factors which affect the nurse's contribution in PE, such as their skills/capabilities, environment, organisational culture, collaboration and support between multiple teams [11].

Various challenges and barriers of PE have been identified in the literature affecting PHcN's attempts to educate patients. Crawford et al. [18] found that cultural diversity and language differences were a potential barrier that impacted PE activities. Efraimssn et al. [19] and Abbasi et al. [20] also identified communication barriers to PE activities and programmes. Another barrier identified from the literature was a lack of support to nurses from the management as well as higher workload which affected their ability to engage in PE programmes [11, 20]. Smith et al. [21], Abbasi et al. [20] and Kok et al. [22] identified that nurses were not provided with a conducive environment for PE which affected their abilities to educate patients. McDonald et al. [23] revealed the lack of appropriate skills in PHcNs in instilling knowledge in patients as well as skills to support PE such as communication skills, listening skills and the ability to simplify tasks for patients for better understanding. On the other hand, Richard et al. [24] noted that nurses often considered PE not a part of their duty and are not willing to engage in the PE programmes.

Healthcare facilities in the UAE, including those in Abu Dhabi, have embraced the Joint Commission International Accreditation (JCIA) standards that underline PE programmes as a basic approach to prevention of diseases, patient treatment

outcomes, as well as quality of life [25]. Despite the compliance requirements, there are limited PE programmes in most UAE healthcare facilities in all Emirates, including Abu Dhabi [15, 26]. It is argued that by and large, PE initiatives are mostly complicated, non-consistent, unsystematic and do not follow evidence-based practice [15, 26, 27]. The UAE and other countries in the region are no exception, and PE is mostly administered by the treating doctor rather than PHcNs [15, 26]. The United Arab Emirates (UAE) needs more PE initiatives, programmes and strategies to further develop PE programmes. This will reduce repeated hospitalisation and recurrences of diseases, reducing healthcare expenses and burden on a country's healthcare facilities as well as on primary healthcare nurses [15, 28]. Although the existing research reveals the lack of appropriate PE programmes in the UAE and their restricted nature, there is a gap identified in the literature regarding the barriers of implementing PE initiatives in the UAE.

Based on the above, the experiences and perceptions of RNs in primary healthcare settings in Abu Dhabi were explored in this study to understand the barriers to PE programmes.

2. Materials and methods

The study utilised qualitative, explorative, and descriptive design research, and the data were collected between July 2020 and May 2021. Qualitative, explorative, and descriptive design research was considered appropriate for the study due to the lack of existing research to explore barriers of implementing PE initiatives in the UAE, and the study thus needed an approach that would allow for gathering detailed data to identify the barriers. Qualitative, explorative, and descriptive design research was considered suitable because of its alignment with interpretivist philosophy, which argued that social reality is multiple, and the individuals are autonomous in their attitudes and experiences [29]. The study attempted to reveal barriers of PE programmes in healthcare facilities of the UAE as experienced and perceived by PHcNs in primary healthcare settings of Abu Dhabi, and thus detailed data was gathered from the research sample.

2.1 Study setting

The study was conducted in and focused on Ambulatory Health Services (AHS) primary healthcare settings in Abu Dhabi. Abu Dhabi is the capital and largest city in the UAE, and it is where the government is located. The Emirate of Abu Dhabi consists of three different districts: the Eastern region (Al Ain), the Western region (Al Gharbia, also known as Al Dhafra), and the Central region. These demographic features influenced the distribution of healthcare facilities and the delivery of healthcare services in Abu Dhabi. The healthcare system was designed to be community-oriented and to provide continuous and coordinated healthcare services to meet the health needs of the population. The country is facing a challenge of diabetes and cardiovascular disease, which account for most chronic disease cases managed in primary healthcare clinics. Non-communicable diseases are estimated to be the main cause of death in Abu Dhabi, accounting for 65.0% of all deaths in the Emirate. As such, this study was conducted in order to explore the perceived barriers in patient education in primary health care settings of Abu Dhabi.

2.2 Population and sampling

The researcher's population was all registered professional nurses who were working at primary health care facilities in Abu Dhabi. Due to the different nature of healthcare facilities in Abu Dhabi, such as public and private, it was considered effective to include a purposive sample from government primary healthcare facilities that are managed by the Abu Dhabi Health Services Company, SEHA and thus a non-probability purposive sampling was used to identify the respondents for the research. Consent from 35 nurses was received, and they participated in the current study.

2.3 Data collection

Data were gathered through semi-structured focus group discussions with participants. Due to the COVID-19 pandemic, the group discussions could not be held face-to-face. As a result, it was decided to host virtual focus groups using the Blackboard platform. Three initial focus groups were performed before calculating the ultimate number of focus groups required. The rationale for beginning with three initial focus group discussions was that Krueger et al. [30] said that focus group-based research should begin with three or four focus groups before choosing whether to continue with more discussions based on data sufficiency and saturation. In this study, data saturation was reached with five focus group discussions. Five FGDs were conducted, with each group including six to nine PHcNs who worked as general nurses in primary healthcare clinics in different regions of Abu Dhabi. In total, 36 PHcNs participated in the focus group discussions. Each group session lasted for 40–50 minutes. A pre-developed list of questions was prepared to interview the respondents. Probing questions were utilised to elicit more rich data where possible and appropriate [30]. The interview questions were open-ended, and great effort was taken to ensure that they did not lead to specific answers [30]. The respondents were first asked to provide information about their gender, age, nationality, and number of years working as a PHcN in Abu Dhabi primary healthcare settings.

2.4 Data analysis

Data analysis began concurrently with data collection. The study's purpose and objectives were utilised to steer the breadth, depth, and strength of the analysis, ensuring that the analysis stayed within the study's framework. This was critical in preventing the researcher from becoming sidetracked by the vast number of data obtained [31, 32].

To organise and code the data and design the study, the QSR NVivo qualitative data analysis software package was employed. The qualitative data gathered were transcribed verbatim and analysed using thematic analysis. Thematic analysis allowed the researcher to detect patterns in the data and then build themes or typologies to characterise these patterns. Braun et al. [33] identified six steps in conducting thematic analysis: familiarisation, generating initial codes, searching for themes, reviewing the themes, defining and naming the themes, and producing the report. In this study, the researcher defined, evaluated, and reported the focus group discussion findings following the steps described by Gammie [30] and Braun et al. [33]. The barriers identified were categorised into three themes, namely barriers related to patients, barriers related to nurses, and barriers related to the physical environment.

2.5 Ethical considerations

Key ethical aspects were considered when this study was undertaken. Firstly, the study was approved by the University of Pretoria Research Ethics Committee with the registration number 239/2020. Permission to conduct the study was obtained from the Institutional Review Boards (IRBs) of the relevant regulatory bodies in the UAE. The respondents were informed about the purpose of the research through a Participant Information Sheet, which provided details about the aims and objectives of the study, the reason for the respondent selection and the utilisation of the research data. The respondents were then asked to sign a consent form which was sent to them by email. The participation in the research was voluntary and no compensation was offered to the respondent, which was clearly conveyed to them. Since the conversation was planned to be recorded, respondents were informed about this in the consent form when asking for their consent. The privacy and confidentiality were ensured, and the PHcN's names and identities were kept confidential. The data were kept safe in a password-protected laptop, and any authorised access was controlled. The risk of COVID-19 was managed through conducting interviews through Blackboard virtual meetings, reducing the risks of social contact and the spread of the infection.

2.6 Trustworthiness

The researcher established trustworthiness by ensuring that the study's findings and arguments supporting the findings are accurate [31]. Different aspects must be considered when addressing the trustworthiness of a qualitative study, including credibility, transferability, dependability, and confirmability [31]. These components addressed the parameters used to improve the trustworthiness of the qualitative portion of this study.

- *Credibility*: Credibility refers to achieving true value in the collected data and focuses on enhancing readers' confidence in the results of the study [31]. Credibility in this study will be guided by prolonged engagement and member check.
- *Prolonged engagement*: Prolonged engagement is one of several strategies that were used to increase the credibility of research findings [31]. In this study, the researcher was knowledgeable about the culture and environment in which the participants worked. The researcher's previous experience in the nursing field helped to build a bond of confidence with participants, which was strengthened by the permission from the relevant ethics committee.
- *Member checking*: Member checking is known as respondent validation and informant feedback, and is a technique used by researchers to help improve the accuracy of a study [31]. In this study, member checking was achieved by returning the data or findings to participants to check for accuracy and resonance with their experiences. This ensured the authenticity of the work.
- *Transferability*: Transferability refers to the extent to which the research results can be applied in other settings or with other groups [34]. Meanwhile, Connelly [35] states that transferability is based on the idea of "applicability" of research findings. That is, the findings may be transferred and/or

applied to another context with similar study settings. To achieve transferability, maximum data saturation was sought in the different focus group discussions.

- *Dependability*: Dependability refers to the extent to which similar findings would be obtained if the study were to be repeated [31]. According to Mohajan [36], this criterion is satisfied if the researcher has established the credibility of the study findings. To assure dependability, the researcher strictly followed the criteria. The researcher coded the data with the help of an independent coder and examined the recordings to ensure that the interview procedures were consistent. The current study included a step-by-step description of the data collection process. By providing a thorough description of the research process, care was taken to ensure that the research process was cohesive, traceable, and clearly recorded in a reflective way.
- *Confirmability*: Confirmability of research findings is related to accurate representation of the information provided by the participants as well as the interpretations of data thereof [36]. In this study, the researcher utilised two strategies, namely, audit trails and reflexivity, to ensure conformability. During the audit trails, various systematic documentation of materials was permitted, and an independent coder concluded the trustworthiness of the study [31].

2.7 Results

The findings of the demographic data are presented in **Table 1**. Most participants were females, and the majority were aged 23–35 years. Most participants held a bachelor's degree in nursing and had 1–15 years of experience working as a PHcN in various healthcare systems. In addition, the majority of participants indicated that they mostly worked the day shift.

The themes identified from the data are presented in **Table 1** according to the categorisation of the data. The three themes and the related categories are discussed below:

Theme	Categories
1. Barriers related to patients	• Negative attitudes towards PHcNs • Not willing to receive PE • Privacy issues
2. Barriers related to nurses	• Language barriers • Communication skills • Considering PE not part of their job as it requires teaching skills
3. Barriers related to physical environment	• Lack of a conducive environment • Lack of appropriate facilities

Table 1.
Themes and categories identified from the data.

2.7.1 Barriers related to patients

Patients are the recipients of PE, and barriers related to patients were noted to be significant in the current study, as observed by PHcNs. Patients were found to think negatively about PHcNs, which affects their willingness to engage in longer conversations with them. From this theme, negative attitude, unwillingness to receive PE, and privacy issues were found to be major barriers related to patients.

2.7.1.1 Negative attitudes towards PHcNs

Participants reported that patients do not take them into account or even to accept them as such; they displayed negative attitudes towards them and the PE activities. Patients look down upon nurses and have in their minds that the work done by nurses is low-ranking; as such, they do not want to engage with nurses. This information was supported by the following quotes:

“We often experience that patients don't acknowledge us, they have a negative mentality towards us, and once in a while they are not able to engage in what we show them, so we cannot do anything in these cases”.

Another participant has added by indicating that;

“Sometimes patients do not accept us, they have a negative attitude towards us, and sometimes they are not willing to participate when we teach them, so what must we do in those cases”.

“Some patients think that ours is a low-ranking job and they do not want to have close interaction with us regarding their disease and treatment”.

2.7.1.2 Not willing to receive PE

Moreover, patients were found to be unwilling and uninterested in PE because of a lack of time, urgency to leave or any other factor. Participants reported that patients will indicate that they were there to see specialists, hence disregarded the health education related to their conditions, even if it is beneficial for their well-being. This was noted from the following quotes:

“Patients are not interested in PE. At the point when you ask them for what reason they say since they don't have time, they came to see the specialist and take medicine also, leave in brief time frame. They are working and that they have different engagements”.

Other participants conquered and further indicated that patients were there to collect their treatment, hence they saw PE activities as a waste of their time as such, they do not see its importance in their lives:

“Patients don't care because they don't want to receive education. When you ask them why they say because they don't have time, they came to see the doctor and take medication and leave in short time. They are working and that they have other appointments. It's a lot of stories”.

“Patients do not understand the importance of PE and how it can impact them”.

2.7.1.3 Privacy issues

Patients’ privacy was not considered when nurses conducted PE activities; as such, their cultural background was not taken into account. This was discovered when there was a breast cancer screening where male nurses were to examine women, and they were not at ease. Patients’ privacy concerns as noted from the below quote:

“We normally implement general PE initiatives which don't consider about our patient culture. For instance, during the breast cancer campaign, many patients were not comfortable with male nurses”.

“We have general programs to perform PE activities, but they do not consider our patient culture. For example, during the breast cancer campaign the number of patients who come to do the exam increases and we have male nurses, whereby some of the patients don't want to be examined by males”.

Another participant reported that patients were not transparent in talking about their problems, hence the issue of privacy.

“Patients are not open with PHcNs and they do not want to discuss their concerns with us. They have privacy issues”.

2.7.2 Barriers related to nurses

Nurses being major stakeholders in PE as they were reported as key barriers to PE activities. From this theme, the following categories emerged: language barriers, communication skills, and considering PE not part of their job, as it requires teaching skills.

2.7.2.1 Language barriers

Participants reported language barriers as a major barrier since UAE is a multi-cultural country with people coming from diverse cultural backgrounds. It was further reported that uneducated patients and those who were old did not understand English; hence, an interpreter was thought of, as such, their information communicated will be distorted. This was noted from the below quote:

“Language is a major barrier, in light of the fact that for the most part we utilize various languages in UAE. Also, at times we have patient who are uneducated or old and they don't communicate in English, so use others to interpret. The issue [is that] now and again I feel they don't react as expected.”

Another participant concurred by indicating that their language will be different from that of the patients, which is a barrier in executing PE activities:

See, my mother tongue is different while the patients' mother tongue is different. Not everyone is good at English. So naturally there is problem in communication.

2.7.2.2 Communication skills

Similarly, PHcN's communication skills were also noted to be a major barrier, as such participants reported that other nurses do not have good communication skills; as such, they cannot educate patients regarding their treatment, leading to poor educational outcomes.

This was revealed below by the following quotes:

"Not all of PHcNs are good in communication and they cannot educate patients about different aspects of their treatment".

"PHcNs might not be good at communication, and they do not know how to convey themselves, this results in poor understanding of the PE communicated to the patients".

Another participant reported the following, which was related to poor communication skills:

"Some of the PHcNs when giving education don't know how to communicate with the patients as such at the end of the day, patients don't remember was taught. I remember one day one nurse gave the education and when she evaluated the education, patients replied differently".

2.7.2.3 PHcNs consider PE not as part of their job, as it also requires teaching skills

Participants reported that PHcNs do not see PE activities as part of their work due to the more critical work they are involved in, and as such, they tend to overlook them. Others reported that they do not have the teaching skills to execute it; hence, they do not see the need to do it. This was revealed below by the following quotes:

"Frankly, the nurses in some cases couldn't care less about it they simply have to finish work and documentation. Thus, you won't ever realize what is the issue for not doing PE, and again when you ask them for what valid reason, they defend their position".

"We have a lot of things to do, and PE might get slipped out of our mind. RNs are usually not trained to teach and do not know how to instil knowledge in patients effectively".

Another participant conquered by indicating issues of having teaching skills as they were not taught on how to teach patients:

"There ought to be specific skills for teaching which RNs might not have as most of us were not trained in teaching".

2.7.3 Barriers related to physical environment

Physical environment is the environment in which PHcNs are surrounded by various challenges. Barriers related to physical environment were found to include a lack of conducive environment, disturbances and noises affecting PE and a lack of appropriate facilities.

2.7.3.1 Lack of conducive environment

Participants reported that the environment in which PE activities are performed is not conducive to such activities. There are a lot of disturbances such as noise where staff members and patients are nearby, some getting in and out. This causes ineffective education at the end of the day. The environment needs to be favourable to support the PE programmes as noted below:

“Viable PE programs ought to be directed in a favourable climate that is supportive of educating patients. There are often disturbances and noises in the surroundings which make it difficult to engage patients and offer them information about the health issues”.

Other participants concurred by indicating that their clinics do not have enough space to offer PE activities, hence they tend to do it even when the environment is not conducive:

“Effective PE activities should be conducted in a conducive environment, but our clinics do not have such space for performing PE activities effectively”.

“PE activities should be conducted in an area that is free from noise of other patients and colleagues, but our clinics do not have such infrastructure for performing PE activities effectively”.

2.7.3.2 Lack of appropriate facilities

Participants felt that they needed a specific space set aside for the provision of PE because it was impossible to provide PE effectively in consulting rooms or waiting areas that were used by many patients. Additionally, participants stated that a proper space would enable them to offer PE in a conducive environment that was free from noise from other patients in waiting areas:

“Moreover, there are lack of facilities such as seating arrangements for patients and nurses where they can sit and talk in a relaxed and easy way”.

“We are usually not provided with a relaxing environment and appropriate facilities to conduct PE where patients also feel willing to cooperate.”

Another participant concurred by indicating that they are using consulting rooms for PE activities, hence other patients who are to be seen end up complaining as PE activities will cause them to stay at the clinic longer than expected:

“We don’t have a space where we can provide PE effectively in our healthcare facility. I am saying space because it is impossible to spend time with the patient in the consulting rooms for people who are sick, and they will complain a lot because they don’t have patience to wait longer in the clinic”.

3. Discussion

The discussion will be guided by barriers to patients, nurses, and physical environment.

3.1 Barriers related to patients

The study revealed several barriers to PE programmes in healthcare settings of Abu Dhabi as experienced and perceived by RNs. Barrier's sourcing from patients was found to be similar to the barriers identified from the literature. Patients were noted to feel negatively towards PHcNs, which impacted their willingness to receive PE. This finding was confirmed by Crawford et al. [18] who argue that there is a significant gap and distance found between RNs due to culture and other issues, which make patients distant from them, affecting their willingness to engage in PE. According to a study conducted by AlSerkal et al. [37] in one of the primary health care services in Abu Dhabi, another barrier to PHC operations, which affected PE, was No-show appointments, where patients came in without appointments, leading to overly populated healthcare facilities. According to the authors, no-show appointments are a significant contributor to inefficiency in PHC operations, which can lead to an estimated 3–14% revenue loss, disrupt resource allocation, and negatively impact health care quality [37]. The study also revealed that patients are unwilling to receive PE since they do not consider it as a major role of their treatment and interventions in their health. Shoaib [36] confirms this finding and argues that patients have varied cultural and religious beliefs, which affect their understanding and role of medical treatment in their health. They either give value to alternative methods of treatment or consider that diseases and cure are in God's hands, and they cannot contribute towards their health. Moreover, the patients were also found to be less interested in PE due to privacy issues. Al Otaibi et al. [38] support this finding and argued that since nurses are considered jobholders at low levels, patients feel more comfortable in sharing and opening up with doctors and not with nurses.

3.2 Barriers to nurses

Various barriers related to nurses were revealed from the study. Nurses and patients were found to speak different languages, which made it a barrier for PE. Crawford et al. [18] corroborate this finding and insist that the first languages of nurses and patients are different and not everyone can easily communicate in a common language such as English, making it difficult to implement PE programmes. Nurses were also found to lack in communication skills from the study, which is supported by Abbasi et al. [20] who argue that not all PHcNs have good communication skills needed to instil knowledge in patients through PE. Primary healthcare nurses are also noted to have limited teaching skills, which affects their ability to engage in PE. It was argued that PHcNs are usually incapable of teaching since teaching requires imparting knowledge in an effective way [18]. Other barriers related to nurses were found to be their attitude of not considering PE as part of their job. Richard et al. [24] confirm this finding by arguing that nurses often consider PE not a part of their duty and are not willing to engage in the PE programmes.

3.3 Barriers related to physical environment

Barriers related to physical environment were found to include lack of conducive environment. Smith et al. [29] also identified that a conducive environment was not offered for PE, which disturbed the PE programmes. Abbasi et al. [20], and Kok et al. [22] also support the finding since they argue that disturbances and noises affect the PE activities. Lack of appropriate facilities, such as seating arrangements, was also revealed to be a physical environment-related barrier, which is confirmed by Abbasi et al. [20] who valued a relaxing and non-disturbing environment for PE initiatives.

The barriers identified from the interviews were found to be supported and corroborated by previous research, and no contradiction was found.

4. Limitations

The study was conducted with PHcNs in Abu Dhabi, and thus, the findings are considered to be limited to Abu Dhabi only. The subjectivity inherent in the data collected in this study is open to criticism since people with varied backgrounds and knowledge can interpret the interview data differently. Various themes and categories were created in this study according to the researcher's own knowledge and experience which might not align with other researchers. This is an inherent aspect of qualitative research and thus was expected. Moreover, the findings were not cross-checked with the respondents due to time limitations which can be considered as a way to affect the reliability of the findings.

5. Conclusions

It was evident from the study that barriers related to patients, as shown by their negative attitudes towards PE, and their unwillingness to receive PE had a negative impact towards their health. Barriers related to physical environment, as indicated by lack of appropriate facilities and of nurses such as language differences, communication skills, and nurses who considered PE not to be their job and teaching skills lead to ineffective patient education.

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Authors' contributions

A.B. conducted the study and drafted this manuscript. T.I.R. and M.D.P. supervised and supported the study and made necessary corrections in the chapter.

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Data availability

The raw data used to support the findings of this study are included in the chapter and can be made available from the first, A.B., upon reasonable request.

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Equity beyond the Protocol: Integrating Ancillary Care in Clinical Trials

Vivi Maketa Tevuzula and Gwen Lemey

Abstract

Ancillary care (AC), medical services addressing health needs uncovered during research but unrelated to study objectives, occupies a critical yet contested space in clinical trials. Unlike protocol-mandated or emergency care, AC responds to incidental conditions such as treating malaria in an Ebola trial, raising ethical and logistical dilemmas, particularly in resource-limited settings. This work examines AC's evolving role in global health research, where trials often expose systemic healthcare gaps, forcing a reckoning with researchers' moral obligations to participants. We analyze six AC models, from Proactive Integration (embedding care into trial design) to Minimalism (restricting care to trial-related harms), highlighting their ethical trade-offs, feasibility, and real-world impacts. Key tensions emerge between individual welfare versus study validity, researcher duties *vs.* systemic inequities, and short-term interventions *vs.* sustainable health systems. By bridging the gap between protocol-driven science and participant-centered care, AC models can transform clinical trials from extractive enterprises into vehicles for holistic health justice. Ideally, AC should be institutionalized by sponsors, researchers, and policymakers as a core component of ethical research, one that honors the dignity of participants beyond the confines of study protocols.

Keywords: ancillary care, research ethics, global health equity, clinical trials, community engagement, resource-limited settings

1. Introduction

Ancillary care (AC) refers to medical services provided to research participants to address health needs discovered during a study but unrelated to its primary objectives. Unlike other forms of care in clinical trials, such as protocol-mandated interventions, emergency treatments, or humanitarian aid, AC occupies a distinct ethical space.

- Standard trial care includes interventions required by the study protocol (e.g., investigational drugs and safety monitoring).
- Emergency interventions address acute, trial-related harms (e.g., anaphylaxis from a study drug).

- Humanitarian aid encompasses broad health services for communities, regardless of research participation.

In contrast, AC responds to conditions outside the study's focus (e.g., treating malaria diagnosed during an Ebola trial) and is participant-specific, arising from the researcher-participant relationship.

AC has become a focal point in debates over equity in clinical research, particularly in resource-limited settings where healthcare systems are strained. Trials in such regions often expose systemic gaps, forcing difficult questions: *What responsibility do researchers bear for participants' unrelated health needs?*

AC is neither purely altruistic nor universally mandated, yet its thoughtful implementation can mitigate global health disparities. By addressing immediate needs and fostering trust, AC bridges the divide between research and local health priorities. However, this responsibility is not absolute; it must be balanced against scientific objectives, feasibility, and sustainability [1–3].

Researchers thus navigate dual roles: as investigators upholding trial integrity and, at times, as de facto healthcare providers. This tension underscores the need for clearer ethical frameworks to guide AC provision [2, 4].

The discourse on AC has matured, grounding researchers' responsibilities in principles of equity, reciprocity, and harm reduction. Key arguments posit that by identifying unmet health needs, researchers incur moral obligations, especially in marginalized communities [5, 6].

Yet challenges persist. Outbreak clinical trials, such as those during the 2014–2015 Ebola epidemic, reveal systemic weaknesses: fragmented coordination, delayed care, and inadequate preparedness [7, 8]. Despite these barriers, studies succeeded through adaptive protocols, infrastructure investment, and community engagement [9–12]. These cases highlight the necessity of ethical foresight and local partnership in crisis research.

A central dilemma remains: *How, when, and to what extent should researchers provide AC?* Community-based trials, with their complex social dynamics, demand nuanced approaches [13]. Proposals range from a capacity-based model (aligning AC with researchers' ability to respond) to broader moral obligations tied to feasibility and the depth of researcher-participant relationships [14, 15].

1.1 Practical concerns also loom

- Adverse selection (participants enrolling primarily for care).
- Moral hazard (over-reliance on research teams for non-trial care).
- Equity gaps (why provide AC only to trial participants when others share similar needs?) [16–19].

Calls for structured guidelines, like those from Malawian stakeholders [20], reflect a fragmented ethical landscape where AC standards vary widely across diseases and regions [21].

1.2 Toward a balanced approach

The path forward requires context-sensitive models integrating:

- Community engagement to align AC with local priorities.
- Collaborative partnerships to share resource burdens.
- Flexible protocols that uphold ethics without compromising study viability.

Later in this work, we introduce the Four P's framework, Participants, Partnerships, Priorities, and Practicalities, as a structured lens for evaluating AC in global health research.

2. Integrating ancillary care models: A comparative framework

The provision of ancillary care (AC) in clinical research is not a one-size-fits-all endeavor. Rather, it is a dynamic interplay of ethical imperatives, logistical realities, and contextual constraints. Across the spectrum of global health trials, from tightly controlled facility-based studies to large-scale community interventions, researchers must navigate a mosaic of approaches to AC, each with its own philosophical underpinnings and practical ramifications.

This section examines six predominant AC models, dissecting their structural architectures, ethical trade-offs, and real-world applications. By juxtaposing these frameworks, we illuminate the tensions between scientific rigor and participant welfare, between short-term feasibility and long-term equity, tensions that lie at the heart of ethical research in resource-limited settings.

2.1 The proactive integrated model: Ethics by design

2.1.1 Conceptual foundations

The proactive integrated model embodies the principle that ancillary care cannot be an afterthought; it must be woven into the very fabric of trial design. This approach anticipates health needs through stakeholder consultations, embeds AC into protocols, and allocates dedicated resources, financial, human, and infrastructural, before the first participant is enrolled. It treats AC as a core ethical requirement rather than an ad hoc obligation.

2.1.2 Case example

The SEARCH HIV trial in Uganda [22] epitomizes this model. By integrating screening and treatment for hypertension and diabetes into its HIV testing campaigns, the study not only bolstered retention rates but also addressed systemic gaps in chronic disease management, a testament to the multiplicative impact of proactive AC.

2.1.3 Strengths

- Trust-building: Demonstrates commitment to participant welfare beyond narrow study objectives.
- Health equity: Aligns research with local priorities (e.g., malaria care in endemic regions).

2.1.4 Challenges

- Resource intensity: Demands robust budgeting (e.g., Merritt et al. found AC costs often underestimated by 30–40%) [4].
- System distortion: Risks diverting local health workers from routine care [5].

2.2 The reactive ad hoc model: Flexibility at a cost

2.2.1 Conceptual foundations

In contrast to the proactive model, the reactive ad hoc model operates on an improvisational basis, addressing AC needs as they arise without predefined protocols. Common in facility-based trials, this approach relies on the discretion of onsite clinicians and the serendipity of resource availability.

2.2.2 Case example

The absence of standardized criteria invites inconsistency, as in a malaria trial in Kenya where participants with severe anemia received iron supplements at some sites but not others [15].

2.2.3 Strengths

- Adaptability: Responsive to unanticipated needs (e.g., emergent mental health crises).

2.2.4 Challenges

- Inconsistent care: Violates horizontal equity
- Moral hazard: Researchers may ignore non-urgent conditions to avoid burden
- Ethical tensions
- Legal risks: Courts in South Africa have ruled that ad hoc AC creates a duty of care [18]

2.3 The referral-based model: Leveraging fragile systems

2.3.1 Conceptual foundations

Predicated on the ethos of sustainability, the referral-based model outsources AC to existing health facilities. In theory, this strengthens local systems; in practice, it often exposes the fault lines of underfunded infrastructures.

2.3.2 Case example

- In the marginalized communities, user fees in case of referral can be considered as sum trivial to researchers but insurmountable for participants

- During the 2022 mpox outbreak, referral systems collapsed under surge demand, leaving researchers morally culpable for abandoned participants

2.3.3 Strengths

- Alignment with global health goals: Avoids parallel systems

2.3.4 Challenges

- Illusory access: Geographic barriers disproportionately exclude women and disabled participants [6]
- Ethical paradox
- Referrals may be theoretically equitable but practically unfeasible in marginalized communities

2.4 The hybrid collaborative model: Shared responsibility

2.4.1 Conceptual foundations

This model, increasingly adopted by NGOs like partners in health, combines top-down planning with bottom-up adaptability. By sharing AC burdens with governments and local providers, it navigates the middle ground between idealism and pragmatism.

2.4.2 Case example

Rwanda's TB/HIV program demonstrated how hybrid AC could synergize with national health priorities, using trial resources to train community health workers who remained post-study [23].

2.4.3 Strengths

- Contingency funds: Pre-negotiated with sponsors for unanticipated AC needs
- Tiered partnerships: Academic institutions provide specialist support to district hospitals

2.4.4 Challenges

- Coordination complexity: Requires robust government/NGO collaboration

2.5 The minimalist model: Scientific purism

2.5.1 Conceptual foundations

This model restricts AC *strictly* to emergencies directly caused by study participation (e.g., anaphylaxis from investigational drugs). It prioritizes internal validity and avoids “confounding” healthcare interventions that could distort trial outcomes.

2.5.2 Case example

The 1990s African HIV natural history studies became a cautionary tale; by withholding available antiretrovirals from control groups to observe untreated disease progression, researchers privileged data purity over lives [24], a violation of the Beneficence principle [25]. It was justified as “scientific necessity” but later condemned as unethical exploitation.

2.5.3 Strengths

- Methodological rigor:
 - Eliminates confounding variables (e.g., unrelated treatments affecting primary endpoints)
 - Aligns with traditional clinical trial paradigms (e.g., placebo-controlled designs)
- Resource efficiency:
 - Minimizes costs and logistical burdens (no need for AC budgets or infrastructure)
- Clear boundaries:
 - Simplifies ethical decision-making by limiting obligations to trial-related harms

2.5.4 Challenges

- Ethical violations:
 - Beneficence: Fails to address treatable conditions (e.g., malaria and hypertension) discovered during trials [25]
 - Justice: Exploits vulnerable populations by extracting data without reciprocal care
- Reputational risks:
 - Erodes community trust in research (e.g., HIV trial legacy in Africa [24])
- Scientific shortsightedness:
 - High attrition rates if participants withdraw due to unmet health needs
 - Ignores real-world applicability (e.g., treatments tested in isolation may not reflect clinical practice)

2.6 The field-level algorithm: Ethics in real time

2.6.1 Conceptual foundations

Born from the crucible of the DRC's Ebola epidemic, Lemey et al.'s algorithm represents a breakthrough in operationalizing AC ethics [1]. Its four-axis evaluation (dependency, severity, capacity, and sustainability) provides a replicable compass for outbreak research.

2.6.2 Case example

Used in DRC's Ebola trials to authorize malaria treatment during clinic closures [1].

2.6.3 Strength

- Structured flexibility: Balances urgency with ethical rigor
- Synthesis: Navigating the AC Labyrinth

2.6.4 Challenges

- Proactive and hybrid models shine in community-based trials but demand extraordinary resources
- Referral systems falter where health infrastructures are skeletal
- Minimalism, while methodologically tidy, risks ethical myopia

3. Ethical frameworks for ancillary care: Bridging principle and practice

The provision of ancillary care (AC) in clinical research is not merely a logistical challenge, it is a moral imperative that reflects the evolving conscience of global health ethics. As trials increasingly engage marginalized populations in low-resource settings, researchers confront a fundamental question: *What do we owe participants beyond the strict confines of scientific inquiry?*

This chapter traces the philosophical foundations of AC obligations, examines practical frameworks for implementation, and showcases pioneering case studies where ethical theory has been translated into lifesaving action. At its core, the discourse on AC grapples with three irreducible tensions:

1. Individual welfare vs. scientific validity
2. Researcher responsibilities vs. systemic health inequities
3. Short-term interventions vs. sustainable health system impacts

By interrogating these tensions through the lenses of justice, reciprocity, and beneficence, we illuminate a path toward more equitable research paradigms.

3.1 The moral foundations of ancillary care

3.1.1 Justice: Correcting structural imbalances

The principle of distributive justice demands that the benefits and burdens of research be allocated fairly, a standard often violated when trials extract data from vulnerable populations while providing minimal care in return [26]. Consider:

- A malaria vaccine trial in Mali enrolls participants with parasitic co-infections but provides no deworming treatment, exacerbating baseline health disparities [21].
- Corrective mechanism: The fair benefits framework [27] argues that AC should offset the “opportunity costs” borne by participants in low-resource settings.

3.1.2 Reciprocity: The debt of gratitude

When participants contribute time, biological samples, and risk to advance science, researchers incur a moral debt. This is particularly acute where trials are the sole healthcare access point:

- In the Partners In Health HIV program in Rwanda, providing chronic disease management was framed not as charity but as *reciprocal exchange* for participation [23].
- Limitation: Over-reliance on reciprocity may reduce ethics to transactional calculations [3].

3.1.3 Beneficence and non-maleficence: Beyond “Do No Harm”

The Hippocratic oath’s mandate extends to research settings:

- Positive duty: The identification of untreated hypertension during an Ebola trial creates an obligation to act [7].
- Harm prevention: Withholding AC for incidental conditions (e.g., malnutrition in TB trials) may violate non-maleficence [25].

3.2 From theory to practice: Operationalizing ethics

3.2.1 The Four P’s framework

Adapted from Ravinetto et al. [7], this actionable model distills AC ethics into four pillars detailed in **Table 1**.

3.2.2 Lemey’s algorithm: Ethics in real time

Developed during the 2018–2020 Ebola outbreak, this decision tool evaluates:

1. Dependency: Is the participant relying on the trial for healthcare?
2. Severity: Will withholding care cause irreversible harm?

Pillar	Key questions	Implementation example
Positive duty	What health needs can we reasonably anticipate?	Pre-trial disease burden assessments in Uganda's SEARCH study [22].
Planning	How will AC be budgeted and staffed?	Dedicated AC line items in grants (EDCTP-funded trials).
Partnership	Who shares responsibility for delivery?	Memorandum of understanding with Malawi's Ministry of Health [20].
Practicalities	What referral pathways exist for complex cases?	Emergency transport vouchers in DRC Ebola trials [1].

Table 1.
The Four P's framework.

3. Feasibility: Can researchers provide care without compromising the study?

4. Sustainability: Will intervention create post-trial dependency?

3.2.3 Case application

The algorithm authorized malaria treatment for a vaccine trial participant when clinics were inaccessible due to conflict, a decision that balanced urgency with ethical rigor [28].

3.3 Case studies: Ethics in action

3.3.1 SEARCH study (East Africa): AC as a trust catalyst

- Challenge: Low uptake of HIV testing due to distrust in research.
- Solution: Integrated hypertension/diabetes screening into trial design.
- Outcome: 37% increase in testing uptake; 92% participant retention [22].
- Ethical insight: Addressing *unrelated* health concerns bolstered engagement with *primary* study objectives.

3.3.2 EBOVAC3 (DRC): Algorithmic equity

- Challenge: Non-trial conditions (e.g., obstetric emergencies) threatened participant welfare.
- Solution: Real-time AC assessments using Lemey's framework.
- Outcome: Zero preventable deaths from ancillary conditions.
- Ethical insight: Structured flexibility prevents ad hoc moral distress.

3.4 The unresolved dilemmas

1. Exploitation vs. paternalism:

- Does providing AC incentivize participation coercively? [5].
- Or does withholding it exploit vulnerability? [6].

2. Sustainability:

- Can AC models like Rwanda's TB/HIV program be replicated without perpetual external funding?

3. Accountability:

- When referrals fail, are researchers or health systems culpable? [29].

3.4.1 *Synthesis: Toward a participant-centered ethos*

The ethical frameworks explored here reject the notion that AC is a discretionary “add-on.” Rather, they affirm that:

“The dignity of research participants is non-negotiable; ancillary care is the currency through which we honor that dignity.”

As the next chapter explores, translating this ethos into practice requires community co-creation, innovative financing, and courageous leadership, ingredients as vital as any research protocol.

4. Practical strategies for ancillary care integration: From theory to field implementation

“Ethics without implementation is merely philosophy.”, Adapted from a Rwandan health worker during the SEARCH trial

The moral imperative to provide ancillary care (AC) becomes meaningful only when translated into actionable strategies. This chapter moves beyond theoretical frameworks to present evidence-based approaches for integrating AC into clinical trials, particularly in resource-limited settings. Drawing from successful case studies and documented failures alike, we outline a roadmap for researchers navigating the complex interplay of community trust, financial viability, and cultural appropriateness.

4.1 Community engagement: The foundation of ethical AC

4.1.1 The trust deficit in global health research

Historical exploitation and “parachute research” have left many communities justifiably wary of clinical trials. In West Africa, for instance, the legacy of controversial HIV studies in the 1990s still echoes in participants’ skepticism today [24]. Effective AC implementation must first address this trust gap.

4.1.2 Proven engagement strategies

1. Participatory design

- *Example:* In Malawi’s TB trials, researchers co-developed AC protocols with village elders and traditional healers, leading to higher retention [20].
- *Tool:* Community Advisory Boards (CABs) with veto power over AC scope [30].

2. Transparent communication

- *Innovation:* Uganda’s SEARCH trial used radio dramas in local languages to explain AC boundaries [22].
- *Pitfall to avoid:* Overpromising care beyond trial capacity [18].

3. Long-term partnerships

- *Model:* Partners In Health’s 10-year commitment to Rwandan health systems post-trial [23].

4.2 Resource allocation: Budgeting for ethical obligations

4.2.1 The AC funding paradox

While most of researchers acknowledge AC’s importance, only few secure dedicated budgets [3]. This disconnect undermines both ethics and science. Practical solutions are suggested in **Table 2**.

Warning: Underfunded AC creates moral hazard, researchers may avoid diagnosing conditions they cannot treat [6].

4.3 Tailored interventions: Meeting diverse needs

4.3.1 Beyond one-size-fits-all

Marginalized populations face intersecting barriers:

- **Gender:** In South Africa, female TB participants required childcare to attend.
- **Literacy:** DRC’s Ebola team used pictograms to explain AC limits.

Strategy	Implementation	Case example
Pre-trial costing	Map local disease burdens; budget for top 3 conditions	Ebola vaccine trials in DRC [28]
Flexible funding	Negotiate 15% contingency with sponsors	EDCTP-funded HIV trials
Health system synergy	Pool AC resources with government clinics	Rwanda’s TB/HIV integration [23]

Table 2.
Practical solution to the AC funding paradox.

- Mobility: Nomadic populations in Kenya received mobile AC units during HIV trials.

4.3.2 Innovative approaches

- Cultural mediators
 - Traditional birth attendants facilitated maternal vaccine trials in Ghana.
- Tiered AC
 - Essential care for all vs. subsidized referrals for complex needs.

5. Conclusion and recommendation

Ancillary care (AC) in clinical trials is not merely an ethical afterthought; it is a fundamental component of equitable research, particularly in resource-limited settings where trials often serve as participants' primary access to healthcare. This chapter shows that the provision of AC is fraught with tensions: between scientific rigor and participant welfare, between researcher obligations and systemic health disparities, and between immediate interventions and long-term sustainability. Yet, these challenges do not absolve researchers of responsibility; rather, they underscore the need for deliberate, context-sensitive frameworks that uphold ethical standards without compromising study feasibility.

The comparative analysis of AC models reveals that no single approach is universally ideal. Proactive integration fosters trust and equity but demands substantial resources, while reactive, ad hoc models, though flexible, risk inconsistency, moral hazard, and inequity. Referral-based systems align with sustainability goals but often fail when local infrastructures are fragile or inaccessible. Hybrid collaborative models offer a promising balance, sharing the burden of care with governments and NGOs, yet they require robust coordination. Minimalist approaches, though methodologically clean, often violate core ethical principles such as justice and beneficence. To help navigate these complexities, field-tested tools like Lemey's Algorithm and the Four P's framework provide actionable structures for ethical decision-making that remain sensitive to context, feasibility, and participant needs. Ultimately, the integration of AC reflects a broader moral imperative: clinical trials must not exploit vulnerable populations for data extraction but should instead contribute to holistic health equity. To translate this ethical commitment into operational reality, all stakeholders, including researchers, sponsors, ethics committees, and policymakers, must work collaboratively across several key areas.

Ideally, AC should be institutionalized by sponsors, researchers, and policymakers as a core component of ethical research, one that honors the dignity of participants beyond the confines of study protocols and community partnerships must be strengthened to ensure cultural appropriateness, build trust, and prevent paternalism. Ethics committees must also play an active role by requiring explicit AC plans in trial approvals and monitoring their implementation throughout the research process. At a structural level, trials must reject minimalist approaches in high-burden settings, where withholding AC amounts to ethical neglect. Innovative financing mechanisms, such as AC impact bonds, should be piloted to sustainably fund care

without compromising core research activities. In parallel, monitoring systems should be established to track and disseminate best practices.

The final perspective is clear: the question is no longer whether to provide AC, but how to do so ethically and effectively. As clinical trials increasingly engage marginalized populations, AC must evolve from an ad hoc obligation to a cornerstone of research ethics, one that acknowledges participants not as mere data points, but as partners in global health progress.

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Stakeholder Engagement for Safe Cardiometabolic Risk Assessment at a Community Sports Event in Rural South Australia

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Abstract

Local sporting events and carnivals in Australia provide opportunity to engage with community members who may not otherwise regularly seek medical assessment. Community health improvement activities can serve to a) build health literacy, b) raise awareness of healthy behaviours for disease prevention, c) assess disease risk and/or d) encourage individuals at high risk of disease to seek medical advice. This chapter describes the multidisciplinary expertise and community engagement required for safe activation of cardiometabolic risk assessment, using a regional South Australian sports event for drought-impacted communities as a case study. Supported by the South Australian Government Preventative Health Branch, Fat Farmers Rural Health Initiative, Barmera Monash Football Club, Flinders University International Centre for Point-of-Care Testing (ICPOCT) and Roche Diagnostics, this case study describes key factors for the delivery of community-based cardiometabolic risk assessment using point-of-care (POC) testing. The strategic regulatory and logistical considerations for safely implementing and optimising haemoglobin A1c (HbA1c) and lipid POC testing in community are the focus of the chapter. They include pre-event planning, logistics, promotion, POC test device verification, operator training and competency, client privacy and consent, clinical and scientific governance and health and safety requirements. This chapter challenges the reader to think beyond simplistic 'plug and play' POC testing afforded via technological advancement and implement real-world solutions to minimise pre-analytical, analytical and post-analytical risk. This information will assist in the optimisation of POC test accuracy, accessibility and affordability underpinning community health and well-being improvement models on a larger scale.

Keywords: point-of-care (POC) testing, diabetes, cardiovascular health, risk assessment, community

1. Introduction

1.1 Cardiometabolic disease and prevention in Australia

In Australia, cardiovascular disease (CVD) and diabetes are major contemporary health problems, responsible for significant disability, morbidity and mortality [1–5]. As a result, the secondary drug therapies used to reduce disease progression and the tertiary management of complications associated with chronic CVD and/or diabetes place significant social and economic pressure on the Australian healthcare system [3, 5].

Highlighting the key role of primary disease prevention, the Australian Institute of Health and Welfare recently reported that 36% of the country's burden of disease, including CVD and type 2 diabetes, could be avoided or reduced with improvement to modifiable risk factors, such as obesity, tobacco use, diet and high blood pressure [2]. In this context, cardiometabolic risk assessment, a process which can assist in the identification of people at high-risk of CVD and/or type 2 diabetes who have not yet developed the condition(s), remains fundamental to reducing the current and future impact of these diseases [6].

Consistent with this approach, the main goal of the 2021–2030 Australian National Diabetes Strategy is to prevent people developing type 2 diabetes through lifestyle improvement [7]. The diagnosis of pre-diabetic and diabetic conditions, as well as management of longer-term blood glucose levels in people with diabetes, can be assessed through the measurement of haemoglobin A1c (HbA1c) in blood [7, 8].

Similarly, the National Heart Foundation encourages community members over 45 years (or 30 years for First Nations people) to seek regular heart health checks, including total cholesterol, blood pressure checks and blood glucose [9]. Heart health checks are also particularly important in people with type 2 diabetes, as they have double the risk of developing CVD [7]. This applies to people with long-term diabetes, especially in the presence of microvascular disease and persistently elevated glycaemic levels, who also have a higher CVD risk than people without diabetes [7].

Cardiometabolic risk assessment does not only identify people at high-risk of CVD and/or diabetes, but also encourages early risk factor modification, helps to target medications to those who will most benefit and aids in clinical decision-making [7, 9]. From an ethical perspective, the early detection of CVD and/or type 2 diabetes through the measurement of lipids and HbA1c in blood is acceptable as both diseases a) are deemed important contemporary health conditions, b) are clinically well understood, c) have recognisable latent and early symptomatic stages and d) have acceptable and accessible treatment options [10].

1.2 Point of care testing and opportunistic community health assessment at sporting events

Point-of-care (POC) tests for chronic disease diagnosis and management have an increasingly important role in wide range of clinical and community settings [11]. POC tests can enable faster clinical decision making, improve rapport with patients and reduce referrals to secondary care, subsequently lowering healthcare costs [12].

Flinders University International Centre for Point-of-Care Testing (ICPOCT, Adelaide, South Australia), is a specialist POC testing provider with an established

expertise in the implementation, optimization and evaluation of POC testing for chronic (as well as acute, and infectious) diseases [13, 14]. In partnership with key stakeholders, the ICPOCT has delivered HbA1c POC testing for diabetes diagnosis and management in primary care settings for approximately 25 years [13, 14]. Importantly with comprehensive training and a robust quality framework, the accuracy and precision of the HbA1c POC testing in this setting has been consistently equivalent to that achieved by Australasian clinical laboratories [15].

Embracing the Ottawa Charter of Health Promotion [16] and Australia's national passion for sport, the ICPOCT together with the South Australian Government, SiSU Health, the Shane Warne Legacy and the Victor Chang Institute conducted opportunistic risk assessments for diabetes and CVD using the SiSU Health Station and POC testing for HbA1c and lipids at the 2024–2025 Australian Football League (AFL) Gather Rounds held in Adelaide and surrounding regions [17].

1.3 Fat farmers rural health initiative

Founded in 2012 by three South Australian farmers, the Fat Farmers Rural Health Initiative inspires and encourages rural communities to improve their health and wellbeing through physical activity [18]. Volunteer Fat Farmers co-ordinators host regular community-based health promotions to connect a diverse range of primary producers across the state and beyond. In 2025, a collaborative partnership with the ICPOCT, Government of South Australia, Barmera Monash Football Club and Fat Farmers Rural Health Initiative aimed to engage drought impacted rural communities in mental health promotion and cardiometabolic risk assessment during the Barmera Monash Football Club Mental Health/Corey Siemers Memorial Round (5th July 2025).

1.4 Aim and objectives

The chapter challenges medical science professionals to apply the practical and critical thinking necessary to implement holistic POC testing frameworks, consistent with regulatory best-practice, outside the laboratory setting. Using the Fat Farmers-ICPOCT Barmera initiative as a case study, the aim of this chapter is to highlight the multidisciplinary expertise, industry collaboration and academic partnerships required to deliver high-quality POC testing for health risk assessment in community. These skills are becoming essential as technological innovation in POC testing advances diagnostic accessibility and affordability towards simplistic 'plug and play' solutions, still requiring robust training and quality systems. Detailed regulatory and logistical considerations for pre-event planning, clinical governance, operator training and competency, device connectivity, work health and safety and operating environment emphasise how pre-analytical, analytical and post-analytical risks can be minimised for safer opportunistic POC testing and optimised for scale.

2. Methodology/implementation strategy

2.1 Stakeholder engagement, role and responsibilities

The engagement of key stakeholders with multidisciplinary expertise and connection to the community was essential to the success of the implementation and optimisation of the Barmera cardiometabolic health promotion activity (**Figure 1**).



Figure 1.
The Flinders University International Centre for Point-of-Care Testing (ICPOCT) and Fat Farmers Rural Health Initiative team cardiometabolic risk assessment as part of the Barmera Monash Football Club Mental Health/ Corey Siemers Memorial Round (5th July 2025). Used with permission.

Fat Farmers secured event funding and initiated the partnership with the ICPOCT. Specific roles and responsibilities were assigned to the key stakeholders across four main stages of the community health initiative 1) pre-event management, 2) media promotion and awareness, 3) event activation for community risk assessment and 4) analysis and dissemination of the cardiometabolic risk associated with the POC test results (**Table 1**).

2.2 Pre-event management

2.2.1 Risk assessment and mitigation

Comprehensive risk analyses were performed to identify pre-analytical (before the POC test), analytical (during the POC test) and post analytical (after the POC test) event risks. This included assessment of ethical community engagement, safe operations, infection control, participant consent, specimen collection and POC test processes, as well as environmental conditions and clinical governance. A standard hierarchy of control measures to mitigate risks and reduce exposure to hazards [19] was incorporated in the pre-event co-design with key stakeholder groups. The risk mitigation steps were incorporated into the standard operating procedures and staff training for the event.

Flinders University Human Research Ethics approved the study design, participant consent, clinical governance, data privacy/confidentiality and participant survey (HREC#8793).

2.2.2 Alignment with POC testing requirements

To maximise community safety and minimise the risk of issuing inaccurate cardiometabolic risk assessment, the procedures developed for this event aligned with National Pathology Accreditation Advisory Council (NPAAC) Requirements for Point-of-Care Testing in Australia [20].

Stakeholder	Stage of the Community Health Initiative			
	1) Pre-event Management	2) Media Promotion and Awareness	3) Event Activation	4) Data Analysis
Fat Farmers Rural Health Initiative (in collaboration with the Barmera Monash Football Club Wellbeing Committee and South Australian Government)	Develop, promote and support community-based health promotion Event funding and co-design Connection to Barmera Monash Football Club Wellbeing Committee for associated events	Promotion on the Fat Farmers website/social media platforms Fat Farmers Ambassador mental health keynote address and community dinner Community group morning walk Mental health and cardiometabolic health assessment media campaign	Fat Farmers representation at event (Community/Team Coordinators) POC test promotion	Initial result review Copy of event report
Flinders University ICPOCT	Ethics approval Risk assessment/mitigation Provision of clinical governor, credentialled diabetes educators and POC test operators Set clinical actionable limits Design, deliver and manage quality framework and event standard operating procedures (SOPs) Activate event insurances Order and transport reagents/consumables	Assist event media resource design	Flinders University representation at event Set up POC testing Workstations Quality testing Perform ethical participant testing Clinical post-test script Escalation to clinical team, as required	Initial result review Result analysis Present results to key stakeholder groups Prepare results for publication/event report
Roche Diagnostics	Device loan agreement Reagent/quality control supply Pathologist advice Operator training	Not applicable	Provision of device and reagents	Copy of event Report

Table 1.
Summary of the multidisciplinary expertise, broad roles and responsibilities of event partner organisations associated with the Barmera community health event.

2.2.2.1 Clinical governance

Broadly, healthcare encounters require primary consideration of safe, high-quality care and the patient's rights.

For the Barmera event, a General Practitioner (GP) with extensive clinical experience in diabetes and cardiovascular assessment was formally engaged and was responsible and accountable for the clinical governance of the POC testing (HbA1c and lipids). The GP led the safe and ethical practice through consultation with Roche's medical advisor and the ICPOCT's medical scientific staff during the development and implementation of event policies and the provision of clinical advice at the event. The GP also facilitated communication of the event to local medical professional bodies, setting of criteria and processes for high-risk POC testing result escalation protocols (e.g. HbA1c >8.0% to have random blood glucose testing at the event's first aid station), review and authorisation of operational practices, processes for communication of incidents that may impact patient safety (none were recorded) and provision of medical consultation throughout the event.

2.2.2.2 Device selection

The selection of a small, robust and analytically accurate POC test device was critical for the event. The cobas[®] b 101 (Roche Diagnostics) is an *in vitro* diagnostic (IVD) medical device approved by the Therapeutic Goods Administration (TGA) in Australia for the quantitative measurement of capillary blood biomarkers for diabetes (HbA1c) and lipids (total cholesterol, triglycerides, high-density lipoprotein cholesterol (HDL-C) and calculated low-density lipoprotein cholesterol (LDL-C). The cobas[®] b 101 employs a single-use, closed-cartridge test disc measurement system with rapid time to result (5 minutes for HbA1c; 6 minutes for lipids). The device has been used at high throughput community screening events by the ICPOCT and deemed to perform satisfactorily in the field [17].

2.2.2.3 Device set-up

The POC testing devices (cobas[®] b 101) were provided under loan agreements with Roche Diagnostics. On receipt of the devices, the instrument parameters, including reporting units and the date/time formats were verified or reset to appropriate local settings by ICPOCT scientific staff.

The performance of all cobas[®] b 101 devices was verified prior to the event using the manufacturer's optical check disc and performing lot-specific reagent disc pre-batch quality control testing (normal and abnormal levels) for HbA1c and lipid testing at the ICPOCT laboratory. Devices and cartridge lot numbers passing verification procedures were designated for either HbA1c or lipid profile use and clearly labelled.

2.2.2.4 Staff training and competency

Competency can be defined as having the required knowledge, skills and professional conduct to perform a task and/or end-to-end process according to required operating procedures [21]. POC testing operators must be trained and

deemed competent to operate the device for participant testing in the required setting.

POC testing operators (medical scientists) from ICPOCT undertook comprehensive face-to-face theoretical training delivered by the manufacturer's scientific support team (Roche Diagnostics) one month prior to the event. Training included procedures for safely and competently performing participant testing and result interpretation, education of common sources of error, quality control testing, privacy/confidentiality and workplace health and safety. POC testing operators also completed training delivered by ICPOCT senior scientific staff which included specific pre-test and post-test scripts for client communication, result escalation processes and workstation set-up/pack-up protocols.

Each operator also completed practical competency assessment by testing quality control materials for either HbA1c or lipids on the Roche cobas® b 101 and obtaining results within allowable limits of performance set by ICPOCT and consistent with those expected of a pathology laboratory. The operator was also required to perform a participant test without error prior to being certified as competent for the community event. Competency certificates were issued to staff completing training, with a defined competency period of 1 year. Staff training records, including a competency register was maintained by ICPOCT. There was no competency issues identified prior to, during or after the training that initiated re-training.

Face-to-face training was also provided by ICPOCT senior scientific staff to credentialed diabetes educators prior to the testing event to outline key roles and responsibilities, participant management strategies and customer service expectations, emergency venue procedures and allow pre-event team familiarisation.

2.2.2.5 Eligibility criteria

The manufacturer's intended use and limitations of the HbA1c and lipid assays were reviewed by the ICPOCT, chemical pathologist (Roche Diagnostics) and event clinical governor. Post-review, specific eligibility criteria were developed for the event (**Table 2**).

Eligibility Criteria	Description
Consent	The participant must read the information sheet and provide written and verbal consent for testing.
Age	The participant must be an adult, that is 18 years of age or greater at the time of testing.
Pregnancy Status	The participant should not be pregnant or at risk of being pregnant at the time of testing.
Prior Medical Conditions/ Treatment	The participant should not be receiving medical care for diabetes or cardiovascular management, have pre-existing diabetes or cardiovascular disease or be taking medication for diabetes or cardiovascular conditions at the time of testing.
Comfort	The participant should be comfortable in presenting for capillary blood collection using a single-use, disposable lancet.

Table 2.
Participant eligibility criteria for haemoglobin A1C (HbA1C) and lipid point-of-care (POC) testing at the event.

2.2.3 Logistics

Based on pre-event planning, the aim of the event was to provide free-of-charge POC testing for approximately 50 community participants. This estimation included a projected device throughput of 10–15 minutes per participant, allowing for participant consent, assay time, post-test discussion between operator and participant regarding their cardiometabolic risk and was reliant on an adequate number of workstations (two workstations, with two devices per station) and rotational staff to allow for regular breaks.

Logistic considerations managed by ICPOCT included calculation and ordering of the required volume of cobas® b 101 reagents, sufficient quality materials, consumables, personal protective equipment (PPE, gloves, masks, safety glasses), specimen collection equipment (disposable bench pads, tissues, alcohol wipes, lancets), basic first aid supplies (cotton wool balls, band aids), hand sanitiser, cleaning products and clinical waste disposal. Portable venue workstation boxes and stationary items were also pre-ordered.

2.2.4 Media promotion and awareness

Fat Farmers directly liaised with the Barmera Monash Football Club Wellbeing Committee and the South Australian Government to organise the associated community well-being events for mental health. This included a free community dinner and mental health presentation by a wellbeing coach and mental health advocate (former AFL player and Fat Farmers Ambassador) on 3rd July 2025, a free community walk (4th July), free mental health checks and POC test cardiometabolic risk assessment during the Barmera Monash Football Club Mental Health/ Corey Siemers Memorial Round (5th July 2025). These events were co-branded by Fat Farmers, the Barmera Monash Football Club Wellbeing Committee and the South Australian Government and were promoted by local media and on community socials.

Fat Farmers also worked closely with the Media and Communications and the Rural and Remote Health (South Australia) teams at Flinders University and to develop POC testing promotional materials. An example promotional flyer used for the event is shown (**Figure 2**). During the event lead up, Fat Farmers also utilised local media to educate the community on the importance of heart health and diabetes risk checks as promotion for the POC testing.

2.3 Event activation

2.3.1 Workstation set-up

To maximise participant confidentiality, consumer experience (i.e. wait time), participant and operator safety, device operating environment and test throughput at the event, each workstation was set-up with required stationery supplies, secure laptop with wi-fi, PPE, quality control (QC) material, specimen collection equipment, basic first aid items, cleaning equipment, two cobas® b 101 devices and appropriate clinical and non-clinical waste disposal (**Figure 3**).



Figure 2.
An example promotional flyer for the Fat Farmers Community Health Risk Assessment for Diabetes and Heart Health 2025. Used with permission.

2.3.2 Quality testing

Device maintenance during the event included a daily optical check using the manufacturer's provided optical disc.



Figure 3.

An example of the haemoglobin A1C (HbA1C) and lipid POC testing workstation used for cardiometabolic risk assessment at the Fat Farmers event. The two cobas® b 101 POC testing devices are located immediately left of the Flinders University display banner (yellow). Used with permission.

Analyte (units)	QC Level 1 (Normal)		QC Level 2 (Abnormal)	
	Mean	Imprecision (SD, CV%)	Mean	Imprecision (SD, CV%)
HbA1c (%)	4.8	(0.1, 2.7%)	8.9	(0.3, 3.6%)
Total Cholesterol (mmol/L)	3.91	(0.07, 1.90%)	6.89	(0.10, 1.50%)
Triglyceride (mmol/L)	1.18	(0.04, 3.40%)	4.29	(0.04, 1.00%)
HDL-C (mmol/L)	0.93	(0.03, 3.02%)	1.90	(0.03, 1.66%)

Table 3.

Summary of point-of-care (POC) test results for quality control (QC) material Level 1 (normal) and Level 2 (abnormal) for % haemoglobin A1C (HbA1C) the concentration of total cholesterol (mmol/L), triglyceride (mmol/L) or high-density lipoprotein cholesterol (HDL-C, mmol/L) on the cobas® b 101.

Prior to QC testing, the HbA1c and lipid lot-specific QC information discs were required to be inserted into each POC device to automatically load the manufacturer's target values and ranges for the appropriate lot number of QC materials into the POC device. However, the actual QC imprecision limits used during the event were derived from independent (ICPOCT) reagent lot verification testing in the laboratory (refer **Table 3**).

Prior to participant testing, normal (Level 1) and abnormal (Level 2) QC materials for HbA1c (cobas® HbA1c Control, Roche Diagnostics) or lipids (cobas® Lipid Control, Roche Diagnostics) were tested on each allocated POC test device at each workstation.

2.3.3 Participant consent

A pre-test participant information consent form (PICF) was developed in conjunction with medical advisors and approved for use by Flinders University Human Research Ethics Committee. Volunteer participants who met the eligibility criteria were asked to read the PICF and provide written consent (signature) for testing. Upon consent, participants were assigned a unique identification number and participant information (postcode of residential address, sex, age (range) and date of last GP visit) was recorded by the POC test operator. Records of the PICFs were stored confidentially during and post-event.

2.3.4 Specimen collection

POC operators collected a capillary whole blood sample from each participant. The HbA1c and lipid reagent discs required the application of 2 and 19 µL of capillary blood respectively.

2.3.5 POC testing for HbA1c and lipids

2.3.5.1 Analytical method for cobas® b 101 HbA1c

The cobas® b 101 HbA1c reagent disc is an *in vitro* diagnostic test for the quantitative determination of % haemoglobin A1c (Diabetes Control and Complications Trial (DCCT)/National Glycohemoglobin Standardisation Program (NGSP)) and mmol/mol haemoglobin A1c (International Federation of Clinical Chemistry and Laboratory Medicine (IFCC)) in capillary blood by latex agglutination and photometric transmission (measurement range: 4–14% (DCCT/NGSP) or 20–130 mmol/mol (IFCC)). The method is standardised against the IFCC reference method for the measurement of HbA1c in human blood, with results traceable to DCCT/NGSP by calculation.

2.3.5.2 Analytical method for cobas® b 101 lipid profile

The cobas® b 101 lipid reagent disc is an *in vitro* diagnostic test for the quantitative determination of total cholesterol (TC, mmol/L), high-density lipoprotein cholesterol (HDL-C, mmol/L), and triglycerides (TG, mmol/L) in human capillary blood by enzymatic degradation and photometric detection. The cobas® b 101 calculates the LDL cholesterol (LDL-C) using the Friedewald formula [22]; noting the formula is only valid where the concentration of triglycerides is <4.52 mmol/L. The cobas® b 101 also calculates the TC/HDL ratio as well as the non-HDL cholesterol (TC – HDL) from the measured values, where the measured data are available.

2.3.6 Recording of participant HbA1c and Lipid POC test results

Delay, failure or error in the communication of test results is one of the contributing factors in serious adverse events and is a major preventable cause of participant harm. Whilst an electronic information system is preferred to minimise post-analytical errors, participant HbA1c and lipid POC test results at this event were manually transcribed onto a workstation and a participant result sheet and doubled checked. Result interpretation for the participant was aided by colour-coded stratified risk ranges derived from Diabetes Australia (for HbA1c) and the Victor Chang Heart Health Guidelines (for lipids) (**Table 4**).

POC operators verbally communicated the participant's cardiometabolic risk to them using scripted post-test commentary developed with clinical advice. Consistent with the scope of practice for medical scientists in Australia, POC operators did provide any specific POC test result interpretation, clinical or dietary advice to participants. Participants with risk considered higher-than-expected (red) were immediately referred to the diabetes educator and/or clinical governor on-call.

Test (units)	Low Risk	Moderate Risk	Higher-than-expected Risk
HbA1c (%)	<6.0	6.0–6.4	≥6.5
Total Cholesterol (mmol/L)	<5.5	5.5–6.5	>6.5
Colour Code	Green	Orange	Red
Requested Action/Discuss with GP	At next routine visit	Within the next month	Within the next 1–2 weeks

Table 4.

Summary of the haemoglobin A1C (HbA1C) and total cholesterol (TC) risk assessment stratification used at the event.

2.3.7 Post-test participant survey

Following the POC tests, participants were asked to complete an 8-question survey (Qualtrics) as shown in **Table 5**. Participants ranked their responses according to a 5-point Likert scale (from strongly disagree to strongly agree).

Number	Question Asked
1	The point-of-care (POC) test process was straightforward and easy to complete as a participant.
2	My general risk assessments for diabetes and heart health, obtained by POC testing, were well explained to me and easy to understand.
3	The staff who performed the POC tests were friendly and professional.
4	I would encourage my friends and family to have their diabetes and heart health risk assessments done by POC testing.
5	I intend to discuss my POC test results with my GP.
6	My POC test results made me aware of a health risk I did not previously know about.
7	I believe POC testing can support the rural health initiative led by Fat Farmers.
8	I would like to see POC testing made available at other community events.

Table 5.

Post-test participant survey questions used at the cardiometabolic risk assessment event.

3. Results

3.1 Assay performance (imprecision) on the cobas® b 101

Target values and acceptable ranges for each QC [Level 1 (normal) and Level 2 (abnormal)] were set during repeated (n = 24) testing conducted by ICPOCT scientists prior to the event; acceptable limits were consistent with those specified by the royal college of pathologists of australasia quality assurance programs (RCPAQAP) and used by Australasian laboratories. The imprecision (standard deviation (SD), % coefficient of variation (%CV)) observed for each analyte during the target setting process (n = 24) is shown in **Table 3**. All QC test results conducted during the event (n = 6) fell within the acceptable ranges.

3.2 Participant demographics

Using two workstations with dedicated HbA1c and lipid POC testing devices at each workstation for approximately 5.5 hours, a throughput of 5.7 participants tested per hour was achieved at the community event.

The total of 63 participants volunteered for assessment of cardiometabolic risk at the Fat Farmers Barmera campaign. Most participants identified as female, were aged between 45 and 54 years and had visited a GP within the last 12 months (although the reason for GP visit not specified). The participant demographics have been summarised in **Table 6**.

Most participants (n = 23, 38.1%) resided in the same postcode (5345) as the event or within the local surrounding areas (n = 29, 46.0%). There were two interstate (Western Australian) participants (6018). **Figure 4** shows the distribution of voluntary event participants by postcode.

Characteristic	Participant Total (n = 63) n (%)
Gender*	Male
	29 (46.0)
	Female
	34 (54.0)
	Non-binary
	0 (0)
Age	18–24
	2 (3.2)
	25–34
	4 (6.4)
	35–44
	8 (12.7)
	45–54
	29 (46.0)
	55–64
	8 (12.7)
	65–74
	9 (14.3)
	75–84
	3 (4.8)
	85 or greater
	0 (0.0)
GP visit in last 12 months (reason not specified)	Yes
	51 (81.0)
	No
	12 (19.0)

*Gender as per the participant response (i.e. where gender is defined as the socially constructed characteristics of women, men, girls and boys).

Table 6.
Summary of cardiometabolic risk assessment event participant demographics.

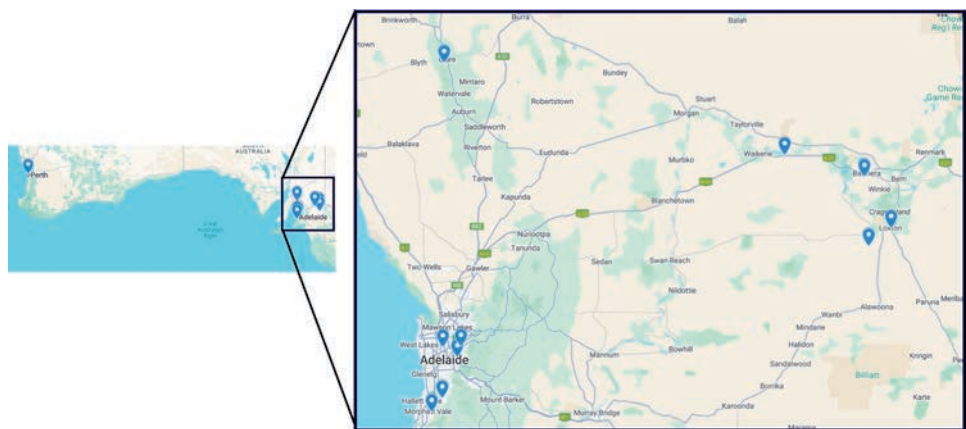


Figure 4.
Map of Lower Western Australia and South Australia (left) showing participant residential location by postcode. Enlarged map of local region of South Australia (right) showing participant residential location by postcode.

3.3 Diabetes risk

Most participants ($n = 60$, 95.2%) were considered at low risk of diabetes, with reported HbA1c less than 6% (**Table 7**). Three participants were at moderate (6.0–6.4%) or high ($>6.5\%$) risk of diabetes. Of these, one male participant was at moderate risk of diabetes and advised to visit a GP within the next 4 weeks. One male and one female participant were at high diabetes risk and were unaware of this risk prior to the POC test. Participants at a moderate or high risk of diabetes at the community event received post-test advice from the on-site diabetes educator and clinician on-call and were actively encouraged to seek follow up with the GP.

Diabetes Risk HbA1C (%)	Participant ($n=63$)	Gender*	Participant HbA1c (%) Range
Low $<6.0^*$	27	Male	4.7–6.0
	33	Female	4.9–5.9
Moderate 6.0–6.4	1	Male	6.1
	0	Female	Not applicable
High $>6.5^*$	1	Male	11.8
	1	Female	6.8

*Cobas® b 101 HbA1c measuring range 4–14% (DCCT/NGSP).

*As there were no participants who identified as non-binary (refer **Table 6**), gender categories in this table were truncated to male and female only.

Table 7.
Breakdown of participant diabetes risk as determined by low, moderate or high haemoglobin A1C (HbA1C) point-of-care (POC) test result.

3.4 Cardiovascular risk

3.4.1 Total cholesterol

Overall, 41.2% of participants had a total cholesterol within the moderate (5.5–6.5 mmol/L) or high CVD (>6.5 mmol/L) risk range (**Table 8**).

Cardiac Risk Total Cholesterol (mmol/L)	Participant (n=63)	Gender*	Participant Total Cholesterol Range (mmol/L)
Low <5.5*	12	Male	3.15–5.28
	25	Female	3.53–5.48
Moderate 5.5–6.5	16	Male	5.62–6.40
	7	Female	5.79–6.35
High >6.5*	1	Male	7.88
	2	Female	6.67–6.96

*Cobas® b 101 TC measuring range 1.28–12.95 mmol/L.

*As there were no participants who identified as non-binary (refer **Table 6**), gender categories in this table were truncated to male and female only.

Table 8.

Breakdown of participant cardiovascular disease (CVD) risk as determined by low, moderate or high total cholesterol (TC) point-of-care (POC) test result.

3.4.2 High-density lipoprotein cholesterol (HDL-C)

Less than half of the participants (45.2%) had HDL-C within the desirable range (>1.5 mmol/L) (**Table 9**). One male participant did not have a HDL-C result reported (error).

High Density Lipoprotein Cholesterol (HDL-C) (mmol/L)	Participant (n = 62)	Gender*	Participant HDL-C Range (mmol/L)
No Rating < 1.5*	20	Male	0.8–1.44
	14	Female	1.02–1.49
Desirable >1.5*	8	Male	1.52–2.15
	20	Female	1.51– > 2.6

*Cobas® b 101 HDL-C measuring range 0.38–2.60 mmol/L.

*As there were no participants who identified as non-binary (refer **Table 6**), gender categories in this table were truncated to male and female only.

Table 9.

Breakdown of participant cardiovascular disease (CVD) risk as determined by desirable High Density Lipoprotein Cholesterol (HDL-C) point-of-care (POC) test result.

3.4.3 Total cholesterol (TC): High-density lipoprotein cholesterol (HDL-C) ratio (TC/HDL-C)

When the ratio of total cholesterol/HDL-C was used, 11.5% of participants considered at high CVD risk, with the majority male (**Table 10**). The total cholesterol/HDL-C ratio was unable to be calculated for one male participant as the HDL-C result was above the dynamic range of the assay (>2.60 mmol/L).

3.4.4 Triglyceride

Overall, 63.5% of participants had a triglyceride within the borderline (1.7–2.5 mmol/L) or high (>2.5 mmol/L) CVD risk range (**Table 11**).

TC:HDL-C Ratio [*]	Participant (n = 62)	Gender [*]	Participant Chol/HDL Range
Very Desirable <3.5	10	Male	1.9–3.3
	27	Female	1.9–3.4
Desirable 3.5–5.0	13	Male	3.6–5.0
	4	Female	4.0–4.9
High >5.0	5	Male	5.1–6.4
	2	Female	5.3–5.4

^{*}Where the measured values (TC or HDL-C) data are not available (ie. greater or less than the analyte measuring ranges), the TC/HDL ratio was not reported.
^{*}As there were no participants who identified as non-binary (refer **Table 6**), gender categories in this table were truncated to male and female only.

Table 10.

Breakdown of participant cardiovascular (CVD) risk as determined by very desirable, desirable or high total cholesterol (TC): High Density Lipoprotein Cholesterol (HDL-C) ratio (TC/HDL-C).

Triglyceride (mmol/L)	Participant (n = 63)	Gender [*]	Participant Triglyceride Range (mmol/L)
Desirable 0.5–1.7 ⁺	8	Male	0.61–1.67
	15	Female	0.56–1.56
Borderline 1.7–2.5	11	Male	1.70–2.42
	9	Female	1.72–2.34
High >2.5 ⁺	10	Male	2.53–7.35
	10	Female	2.52–4.20

⁺Cobas[®] b 101 triglyceride measuring range 0.5–7.35 mmol/L.
^{*}As there were no participants who identified as non-binary (refer **Table 6**), gender categories in this table were truncated to male and female only.

Table 11.

Breakdown of participant cardiovascular (CVD) risk as determined by low, moderate or high triglyceride (TG) POC test result.

3.4.5 Low-density lipoprotein cholesterol (LDL-C)

Overall, 83.1% of participants had LDL-C within the borderline (1.7–2.5 mmol/L) or high (>2.5) CVD risk range (**Table 12**), noting that the Friedwald formula used to calculate the LDL-C was reported within the manufacturer's IFU as not being valid for non-fasting patients or those with Type III hyperlipoproteinemia (dysbetalipoproteinemia). Four participants (three males and one female) were unable to have an LDL-C calculated as their triglyceride result was >4.52 mmol/L.

3.5 Participant feedback

A total of 25 (39.7%) participants undertaking POC testing at the community event responded to the post-test survey. All (100%) respondents strongly agreed with the ease of the POC test process (question 1), the ease of understanding the cardiometabolic risk commentary provided to them (question 2), the professionalism

Low Density Lipoprotein Cholesterol (mmol/L)*	Participant (n = 59)	Gender*	Participant LDL-C
Not rated <0.5	0	Male	Not applicable
	1	Female	0.26
Desirable 0.5–1.7	6	Male	0.62–1.40
	3	Female	1.49–1.69
Borderline 1.7–2.5	1	Male	2.33
	16	Female	1.73–2.39
High >2.5	19	Male	2.52–4.31
	13	Female	2.5–3.98

*Where the concentration of triglycerides was <4.52 mmol/L, the LDL-C was calculated on the device using the Friedewald formula ($LDL = TC - HDL - TG/2.2$ (measured in mmol/L)). Where the concentration of triglycerides was ≥ 4.52 mmol/L, the calculated LDL-C was not reported.

*As there were no participants who identified as non-binary (refer Table 6), gender categories in this table were truncated to male and female only.

Table 12.
Breakdown of participant cardiovascular (CVD) risk as determined by not rated, desirable, borderline or high Low Density Lipoprotein Cholesterol (LDL-C) point-of-care (POC) test result.

and friendliness of the staff (question 3), the likelihood of recommending POC testing to friends and family (question 4), the linkage of the POC testing event in supporting Fat Farmers rural health initiatives (question 7) and the ability to have POC testing available at other community events (question 8). Importantly, 88% of respondents strongly agreed (68%) or somewhat agreed (20%) of their intent to discuss their POC test results with their GP (question 5). However it was noted that only 52% of respondents strongly agreed (40%) or somewhat agreed (12%) the POC test results had made them aware of a health risk that they did not previously know about (question 6), with 24% neither agreeing or disagreeing with this statement (Figure 5).

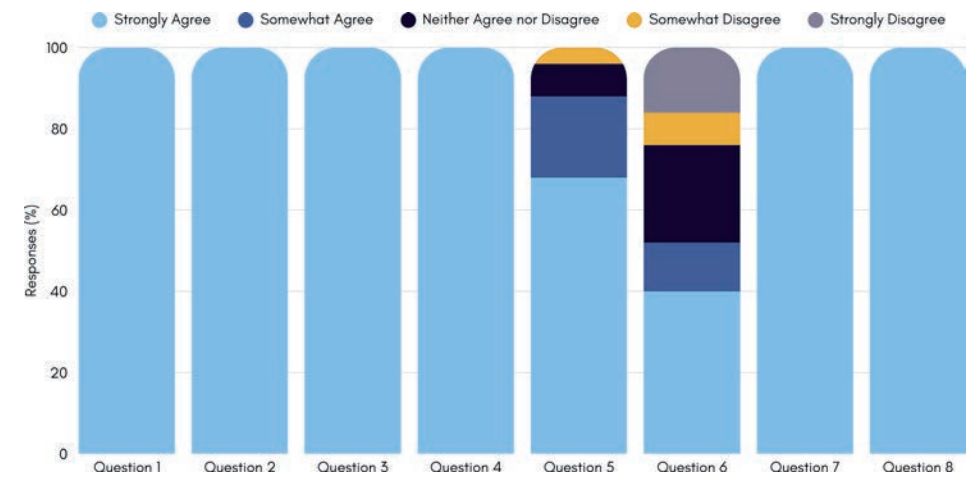


Figure 5.
Participant responses to survey questions (n = 25). Survey questions were listed (previously) in Table 5.

4. Discussion

In our experience at both the 2025 Barmera and AFL Gather Round events, the cobas® b 101 POC testing device was robust, easy to set-up and use in the community. As the testing at the Barmera event was performed inside the football clubrooms, the environmental conditions met the device's operating conditions as specified by the manufacturer. If the cobas® b 101 POC testing device is being considered for use at a community in an outside environment, particularly in Australia, the upper temperature limit (32°C) for device operation may require logistical consideration. This device limitation was experienced at the 2025 AFL Gather Round event, where unseasonal temperatures led to the device being transiently inoperable due to high temperature in the outdoor testing marquees. In this situation, the portable air-conditioning units were insufficient to maintain the temperature below 32°C, leading to temperature-related device errors (no result issued). This was overcome by either cooling the reagent discs or a single workstation (i.e. 2 devices) directly with the airconditioning unit.

The choice to use dedicated cobas® b 101 devices for HbA1c or lipids at each workstation optimised capillary blood collection (e.g. blood could be applied to both reagent discs sequentially) and maximised participant throughput. This allowed the goal of 50 participants to be exceeded at the event ($n = 63$) by facilitating the testing of 5.7 participants per hour per workstation at the community event.

This highlights the need for queue management at larger community events as well as the importance of a) deriving an achievable throughput pre-event, b) creating adequate staff rosters that allow adequate rest breaks to avoid operator fatigue and c) consideration of process development for recalling participants to minimise frustration during waiting periods.

The performance of the reagent lot numbers used for HbA1c and lipid POC testing at the community event were verified in the laboratory using two levels of manufacturer QC (normal and abnormal) prior to batch release. This provided confidence that the reagent discs would perform adequately for participant testing at the community event (pending daily maintenance and QC testing).

The HbA1c POC test exhibited satisfactory precision as determined from the HbA1c QC results achieved across both workstations at the community event. HbA1c QC results exhibited total CVs that were $< 3\%$ for the normal QC and $< 4\%$ for the abnormal QC. Similarly, the observed imprecision was $< 3.5\%$ for all lipids parameters tested. The performance observed meets the analytical benchmarks for these tests in the primary care setting [23].

Most participants who presented for the free POC tests at the community event were aged 45–54, an age range consistent with an increased inherent cardiometabolic risk.

At an individual level, opportunistic POC testing for cardiometabolic risk may alert community members who may be otherwise unaware of diabetes and/or CVD status to seek appropriate medical advice and follow-up. In this context, local GPs and associated relevant professional bodies should be made aware of the community event occurrence. While only 3.2% (2/63) of participants assessed were at high risk of diabetes at this event, borderline/high risk levels of lipids were more prevalent (41, 64 and 83% for total cholesterol, triglyceride and HDL-cholesterol respectively. Nonetheless, the early identification of an albeit smaller pool of participants at risk of diabetes is important when considering that the lower the HbA1c, the lower the risk of developing downstream complications of diabetes (with a 15 percent reduction in HbA1c equating to a reduction in risk of over 35% for both retinopathy and nephropathy [24].

Whilst this study was restricted to a small proof-of-concept pilot there remains a public health need to develop future studies which have the necessary sample size and design to evaluate the cost-effectiveness of cardiometabolic risk assessment using POC testing at community sporting events.

Traditionally, lipid analyses have been performed on a non-fasting sample which has made the interpretation of opportunistic lipid testing problematic. However, there is now an increasing body of work from large scale clinical trials and meta-analyses that show there is no clinical difference in using non-fasting lipids compared to fasting lipids for cardiovascular disease risk assessment [25]. As a result of these studies, consensus statements from a range of prestigious professional bodies all recommend the use of non-fasting lipids for risk assessment, with a repeat of fasting lipids only indicated if non-fasting triglyceride levels are above 4.5 mmol/L or higher [25].

Two important components of the optimisation of POC testing for community risk assessments that were not addressed with the Fat Farmers initiative were (a) electronic transfer and storage of data from the POC testing devices into a mobile phone app for presentation to the participant's GP and (b) assessment of the rate of follow-up with the participant's GP.

The early detection of chronic diseases is now a priority activity for most professional non-government organisations with a diabetes or heart disease focus. In Australia, early identification of chronic kidney disease (CKD) risk is firmly on the agenda for Kidney Health Australia, with a stated goal being the elimination of dialysis by 2025. While analytically sound POC testing technologies exist for diabetes and lipid risk assessment, the same does not necessarily hold true for CKD detection through testing for whole blood creatinine (with associated automatic calculation of estimated glomerular filtration rate (eGFR)). Indeed, an accurate method for blood creatinine is highly sought after at the point-of-care. While some promising technologies are now appearing on the market, they need rigorous analytical evaluation to ensure classification of CKD risk is within clinical specifications. Sound POC testing methods exist for assessment of urine albumin:creatinine ratio (UACR) as a marker of microalbuminuria, but sourcing a spot urine sample in a community setting is often difficult and inconvenient for the participant.

While sporting events offer an appropriate and opportunistic environment for POC risk assessment, other primary care sectors, including pharmacies, may offer even greater opportunities for identification of community members at risk of chronic diseases.

5. Conclusion

The delivery of POC testing for chronic disease risk assessment at multiple community venues supports high-quality POC testing being performed outside of a clinical laboratory. However, multidisciplinary expertise, appropriate clinical governance, trained and competent operators with a robust quality framework are all essential for this to be achieved. Linkage to further care pathways and the downstream capacity of medical practitioner consultation following community POC testing also requires careful consideration for outreach events. Although POC device and test simplification has been evident with technological advances, the implementation of best-practice standards to underpin POC testing is critical in the minimisation of pre-analytical, analytical and post-analytical error and possible patient harm. Inclusion of POC testing at community events, such as the Fat Framers Rural Health

Initiative, mandate extensive planning and logistics, risk assessment and mitigation, derivation of robust standard operating procedures and training, quality control and quality assurance testing, clinical governance, health and safety and environmental considerations.

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Conflict of interest

The authors declare no conflict of interest.

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The present book covers both the traditional concept of community health action models at the community level in a participatory manner and, at the same time, has diversified from community to clinic, addressing equity, quality, and relevance. The book covers chapters from experienced public health experts, their viewpoints, to ensure community health is a reality for marginalized communities in diverse settings in both developing and developed countries. The book has also covered the experience of promoting community health in the community, the workplace, and clinical settings. The book also includes the use of emerging technology for the betterment of society and to address emerging challenges arising from environmental degradation and climate change.

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