



# Inspiring Self-Management Through Peer Leadership

A guide for program design



# Executive Summary

## Why did we produce this toolkit?

Globally, the number of people with multiple chronic conditions (MCC) is rising. Especially in the United States, the rate of this growth is uneven. Due to rising income inequality and racial and ethnic discrimination in medicine, housing, and education, there are stark health inequities between racial and ethnic groups, income groups, and even neighborhoods.

Self-management—i.e., training patients to control their own health—is a promising approach to addressing these

issues. Additionally, training patients to help their peers through health behavior change offers unique advantages in promoting disease self-management.

We designed and pilot-tested a peer-led wellness program to promote self-management for patients with MCC at a large health system in New York City. Via 12 weekly meetings, this peer-support wellness program aimed to provide participants with education (e.g., in areas such as medication adherence, social support, healthy diet patterns, and pain-management), skills training, and peer support as they managed their MCC.



We believe programs like this can help people who have MCC live healthier, longer, and better lives; lower their healthcare costs; and reduce the burden on healthcare workers.

Thus, we have developed this toolkit to guide other healthcare providers and program administrators in adapting this approach for their unique populations.

### **What's inside this toolkit?**

In this toolkit, we provide: a detailed case study on our program (the PeakHealth Wellness Program), this comprehensive guide for program development in other settings, and a digital asset library containing ready-to-print materials to facilitate easy adoption.

### **Who should use this toolkit?**

We designed this toolkit for leaders and staff in primary care settings (e.g., program designers, coordinators, and administrators) who are interested in supplanting traditional, medical primary care with an evidence-based peer-led self-management program for patients with MCC.

While this toolkit is geared toward primary care practices who serve patients in medically underserved communities, the materials and broad content topics make it usable in many settings.

Though we piloted this program in a medical setting, we believe it could also be used by community leaders or social service organizations that serve community members with MCC.



WE Did  
This  
Together

I AM  
Peak Health

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# Introduction and Background

## The problem

Almost half of all adults in the United States (42%) have more than one chronic condition. The risk of having multiple chronic conditions (MCC) rises as people age: 81% of US adults over the age of 65 have MCC.<sup>1</sup> Having MCC means managing a series of complex tasks: multiple healthcare appointments; many medications (in some cases 10 or more per day);<sup>2</sup> changing diet and physical activity patterns; managing and living with chronic pain; high healthcare costs; and often anxiety, depression, and stress.

Having MCC may lead to disability and functional decline, and decrease wellbeing and quality of life.<sup>3,4</sup> Medical care for patients with MCC is more complex as well: healthcare providers must track myriad patient needs, and manage referrals and medications. Yet they are often unable to address underlying causes or provide cures. In the United States, care for patients with MCC accounts for an estimated 70% of all healthcare spending.<sup>5</sup>

## The problem (cont'd)

Rates of MCC are unevenly distributed across the United States. Individuals who are living in poverty, have less education, or are people of color (i.e., African American, Hispanic, Latinx) are disproportionately affected by MCC.

The uneven distribution of MCC by socioeconomic status and neighborhood is due in large part to the historical legacy of housing, employment, and social discrimination including by race, ethnicity, and income. Indeed, a recent analysis of insurance claims data for patients who receive Medicaid in New York City found that 61.5% of patients had two or more chronic conditions—significantly higher than the national average.<sup>6</sup>

## A challenge to health systems

Mount Sinai Health System is located between two neighborhoods: the Upper East Side and East Harlem. The Upper East Side is a mostly white, high-income neighborhood where the average household income is over \$200,000/year.<sup>7</sup> East Harlem, its neighbor directly to the north, is racially and ethnically diverse and has one of the lowest average household income levels in New York City, at \$60,000/year.<sup>8</sup> This disparity means that Mount Sinai Health System serves a vastly diverse population, and must consistently innovate to ensure quality healthcare to all patients.

Health systems across the United States have begun to respond to these challenges through intensive primary care. Providers and hospital systems must meet specific quality benchmarks, focusing more on prevention and carefully managing patients with chronic diseases, in order to avoid costly and dangerous emergency room visits and long hospitalizations.<sup>9</sup> This

practice model is variable, but may include the following components:

- Targeting so-called “high risk” patients—those who utilize emergency care, but face myriad barriers to accessing consistent primary care (e.g., cost, language, time, and trust)
- A “pod” provider model, in which cross-functional teams (i.e., primary care physician, care coordinator, pharmacist, social worker) work together with a consistent patient case load, so the team and patient get to know each other
- Coordination with social services such as legal or housing advocacy to improve patients’ living conditions

Many of these programs offer an array of preventive measures (e.g., proactive medication management, transportation to and from healthcare visits, and often lifestyle or wellbeing programs), but patients still need to manage their MCC in order to improve their health. Without the knowledge and confidence to control their own health behaviors, even patients in intensive primary care often struggle.

The average visit length at most primary care practices around the United States is ~16 minutes (Tai-Seale, 2007), once per year. During a medical visit, providers and patients may have different priorities—and much to discuss. For example, a study of a primary care facility treating patients with diabetes living in a low-income community found that, during an average 28-minute-long visit, 25 health issues were addressed: 9 just over one minute per health issue. Even at Mount Sinai’s PeakHealth—an intensive outpatient clinic designed to accommodate the needs of vulnerable patients with many chronic diseases—the average primary care visit is only 30 minutes.



Mount Sinai’s PeakHealth program uses a pod model of care—in which social workers, care coordinators, and pharmacists all assist a patient’s primary care provider—to help give patients time to have their voice heard. But even care coordinators and community health workers trained to provide this support may not know as much about the chronic diseases that their patients live with as the patients who live with them.

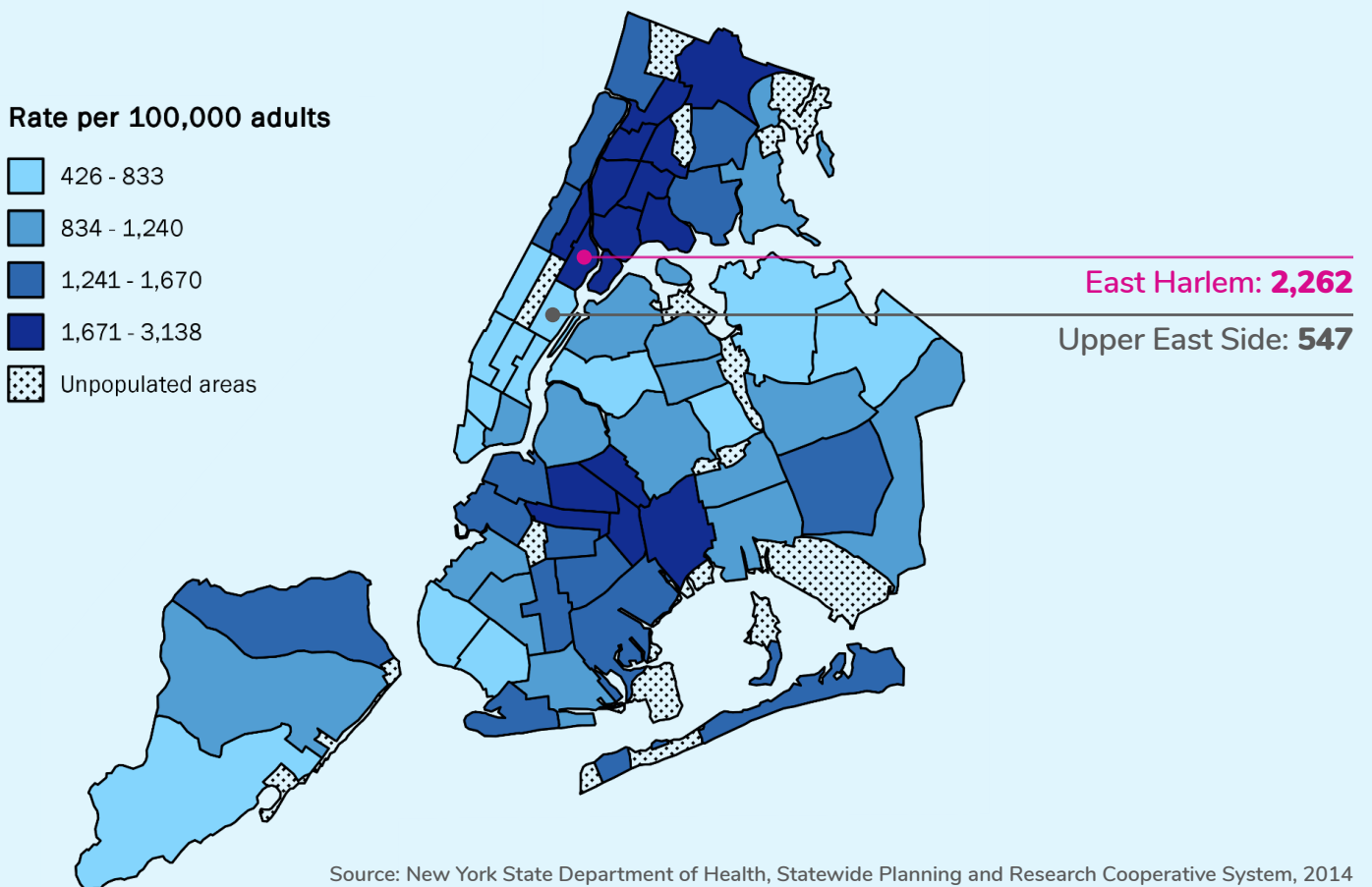
In short, even in the most comprehensive primary care settings, a gap exists between what patients need to control their own health and what their medical home can provide. Patients, providers, and health systems would all benefit from disease self-management training, but it remains unclear who might deliver such a program.

### What is self-management?

Self-management is a solution to this problem: training patients to control their own health. McGowan, et al (2012) define health self-management as, “any intervention which aim[s] to empower patients to be active decision makers who deal with emotional, social or medical management of their illness with the aim of improving their independence and quality of life.” Self-management describes the set of activities a patient needs to complete in order to support their health and manage chronic conditions between healthcare visits.<sup>10</sup>

While specific activities may differ based on type of condition, many activities are

## Avoidable Hospitalizations Among Adults in NYC<sup>11</sup>



shared among conditions, such as taking medications as prescribed; eating a healthy diet (depending on specific dietary needs); getting enough physical activity; leveraging social support; and talking with your doctor. Many adults living with a chronic condition also experience chronic pain, and have co-occurring anxiety, stress, and depression. Most behavior change interventions require meeting for an hour or more per week, for at least 6-10 weeks. The process takes time, because patients with MCC may need to adopt up to 10 behaviors to successfully self-manage.

Our program involves a cross-functional approach to MCC self-management. In collaboration with providers and staff at the PeakHealth program above, we designed a program for high-risk, low-income patients with chronic disease that is adaptable and usable in similar settings. We believe that self-management can help people who have MCC live healthier, longer, and better lives, and that teaching patients how to self-manage at home and empowering them to do so consistently can help health systems lower costs; save lives; and reduce the burden on healthcare workers.

## Peer support: addressing a critical need in primary care

There are many ways to empower patients with MCC to manage their own health. Training patients to help their peers to change health behavior offers unique advantages in promoting disease self-management. First, health providers may lack the time or resources to help patients understand and control their chronic diseases.<sup>12,13</sup> Second, patients may be ideally suited to understanding the challenges of their peers—and their common resources and culture. Third, peer-led groups can provide a shared community

for information sharing, idea generation, and social support—all of which are critical to sustained behavior change.

Crucially, the peer support approach to self-management is not new, but underutilized. Two of the most well-established evidence-based models worldwide are:

- *The Chronic Disease Self Management Program (CDSMP)*<sup>14</sup>
- *The Peers for Progress initiative*<sup>15</sup>

In developing our MCC peer support initiative at Mount Sinai's PeakHealth clinic, we chose to integrate concepts from the CDSMP model—used extensively both in New York City and worldwide—with a care structure we developed iteratively with PeakHealth staff, providers, and patients.

As detailed below, this guide documents our strategy in building and refining that care model. We emphasize that the goal is not to replicate our own model, but rather to use elements of this strategy—in concert with other models such as those above—to build a program that responds best to the needs of your community. We began with our clinic's needs and concerns, and then integrated elements of a separately validated model (the CDSMP) as a second step. But you may decide to pursue these tasks in the opposite order, or simultaneously.

The key is not to replicate our program, or even our approach—but to use our findings to respond to your own clinic and community's unique needs. Throughout the guide, we reference our specific findings and outcomes as an example.

## How to use this toolkit

This toolkit describes the design and implementation of the PeakHealth Wellness Program (PHWP)—the peer-based

behavior change program we built and tested with the PeakHealth Clinic in 2018–20—and provides resources for you to build a similar program in your own community.

You may review the program materials and decide to implement it just as we did—which is welcomed. This toolkit provides guidance on how to deliver this program as it's been piloted, or, specific components may be used separately or in combination.

You may decide that your program may benefit from adaptations. This toolkit provides guidance for modifying the program and will walk you through the process of training peer leaders, recruiting participants, running the program, and evaluating its success. Adaptations can be made to the content, context, cultural and geographic references, or program delivery.

A key element of our approach was to design the program to adapt to the unique needs of PeakHealth. Even if you choose to make few changes to the materials or program, we suggest you consider whether and how you need to adjust its delivery to suit your own needs. For instance, where will the program take place or how you train peer leaders. The sections below on Assessment and Adaptation can help.

This toolkit is meant to guide healthcare providers and program administrators to adapt the PHWP to be useful for their populations. We recommend reading this guide all the way through, and then focusing on the sections that make sense for your program.

## **A word on COVID-19 and similar pandemics**

We are aware that, as of mid-2020, the pandemic of COVID-19 has radically transformed the delivery of healthcare

worldwide. COVID-19 poses a new, acute, potentially life-threatening challenge to all patients—but is especially severe, and especially lethal, in persons who live with MCC. Furthermore, it provides major logistical barriers to access to chronic disease care exactly when patients need it most. And the dual threats of this new disease and weakened access to care have caused and exacerbated mental illness among vulnerable populations worldwide.

We do not know what long-term form the COVID-19 pandemic will take, if any. However, we strongly believe that a focus on the primary care needs of persons with chronic disease is not a distraction from the urgent global response to COVID-19, but an essential component of it.

And the innovative strategies already underway worldwide to adapt chronic disease care to prevent and treat COVID-19 infection may yield novel care models (including for disease self-management and peer support!) that persist even when the pandemic abates. Examples of such models include an online platform for the CDSMP care program, called Better Choices, Better Health, among others.

We are mindful that the strategies we share below—developed and written before the onset of the pandemic—will require modification to comply with current restrictions and closures. We are undertaking these adaptations now at PeakHealth (see Evaluate your Program section), incorporating strategies developed by the creators of CDSMP.

We will share these results on our website as well.



# 01

## Assess

# Stakeholder Needs

Before undertaking an adapted peer support program, consider what resources and skills your stakeholders have, and what they are seeking. This work involves not just sizing up physical resources, but also

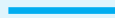
- 1) assessing your team's current knowledge and skills related to activities of self-management;
- 2) defining gaps between where knowledge, skills, and behaviors are currently and where they should be;
- and 3) adapting your program to best leverage your knowledge, resources, and assets while addressing remaining needs.

Conducting a needs assessment will also help identify which aspects of our below program (the PHWP) align well with your priorities and which need to be modified—and it will allow you to get “buy-in” from leaders in your setting. The ability of your program to sustain itself, and scale up in size, depend not only on the program's effectiveness, but also how feasible, acceptable, and appropriate it is to your stakeholders.



## **Orienting Questions**

With all your team members, use these questions to inform and situate your work during this phase:



**Who are the relevant stakeholders?**

**Whom do we want to serve with this program?**

**What is already known about the target population?**

**What are the working assumptions regarding the target population, and how can the needs and assets assessment challenge them?**

**From whom should we solicit feedback regarding needs and assets?**

# Define and engage your stakeholders



## PHWP Example

When identifying our stakeholders at PeakHealth, we immediately named its physicians, nurses, social workers, case managers, and patients.

However, we also spoke with local community organizations; care providers at other centers at Mount Sinai that our patients visit, like pharmacists and pain specialists; and staff at the New York Academy of Medicine, where we hosted our meetings.

**Stakeholders** are all the people whom your program affects. These include those who could benefit from your program, as well as those who might be adversely impacted. Stakeholders are, by definition, all those who need to inform; sign off on; implement; or continue your program. You may not involve each stakeholder at the same level during your needs and assets assessment or in program planning, but the success of every step of the program will depend on identifying and consulting with stakeholders appropriately.

Patient and community stakeholders for a peer-led self-management program, for example, could include not just program participants, but their caregivers and family. Staff and program stakeholders could include not only the core primary care team, but also ancillary care team members (such as pharmacists or specialty care providers). Stakeholders also typically include current and potential program funders (e.g., of a future iteration or duplication of the program). Your stakeholders will likely also be part of your program planning team, and those on that team should be involved in the needs assessment planning phase (below).



## PHWP Example

We also met with colleagues at the Arnhold Institute for Global Health, the research center that led program design—to align our approach with Arnhold's vision for strengthening health care delivery. Further, we engaged members of the Environmental, Social, and

Governance team at Teva Pharmaceuticals—the program's funder—to mutually agree our key goals while maintaining our independence in research and program design. PeakHealth's program manager and lead social worker emerged as key program planners.

# Decide whom to survey

## Considerations

Depending on the questions you want to answer and the size of your team and population of interest, it will probably not be feasible to survey your entire target population. Don't worry—you won't need to survey everyone in your target population. Because self-management is a broad, multi-dimensional concept, you might first decide what behavior changes your program should target—which will narrow down whom to survey.

Regardless of the program content, however, the foundation of any behavior change program is engagement in program activities. Hence, it's helpful to speak to patients whose current level of self-management runs the entire spectrum— from those who are already highly engaged in disease self-management, to those who do not engage at all in self-management behaviors. Doing so will allow you to survey patients who might be likely candidates to become eventual peer leaders, and provide clues about to how to recruit and retain participants. Using these considerations, decide who you will rely on for information about the target population's needs, and how you'll ask them to participate.



# Review existing evidence

## The literature

We designed the PeakHealth Wellness Program following a review of key evidence related to chronic conditions, behavior change, and program implementation in communities that have been historically medically underserved. This includes, for example, the Chronic Disease Self-Management Program (CDSMP) detailed above. This work includes peer-reviewed literature (scientific papers, inspected by other scientists before they were published), but also un-reviewed (called “gray”) scientific literature, and other community-based research, such as reports from prior behavior change programs.



### PHWP Example

Our strategy for the PHWP involved developing a new program derived from several core key elements of the CDSMP model—and incorporating other CDSMP resources iteratively as the program expanded.

**This review** does not have to be exhaustive—a systematic step-by-step review can take months to years to complete. Moreover, there is no need to copy a previous program—adapting others’ work to fit your own community is not just acceptable but essential (and is the key goal of this guide!) But, given the diverse set of programs that already exist, one or more will almost certainly benefit your community’s needs and stakeholders.

Doing this “homework” offers you ideas for what others have done to address community needs, and you can adapt this program to incorporate any additional insights.

# Plan and conduct needs assessment



## Process Note

PeakHealth's lead social worker emerged as a key stakeholder early in our needs assessment. She knew all the patients at PeakHealth, was familiar with many of their stories, and had spent years coordinating services and care for them, as well as advocating for them in various settings.

This expertise, and effort, went far beyond her official role in the program, and we may have overlooked her potential contribution had we not reached out systematically to her and all other staff and stakeholders engaged with PeakHealth to understand their interests, background, and motivation to participate.

## Overview

This step involves deciding both what you need to do, and also who will do which tasks. First, choose the primary methods you'll use to collect data about your target population. Consulting with survey methodology experts in health behavior assessment is a good idea at this stage: they can inform both what content you include in your assessment, in addition to the methods through which you deliver each assessment type.

Broadly speaking, a needs assessment incorporates two types of data gathering: quantitative data and qualitative data. Quantitative data puts the results into numbers, categories, or other specific "boxes" (e.g., through surveys), whereas qualitative data refers to discussions, interviews, or other subjective views.

## Quantitative data collection: surveys

Surveys are pre-written questionnaires that ask a standard set of questions to all respondents. Surveys can be administered in person, over the phone, by mail, or online, and are often used in needs assessment as a first step to determine the prevalence of a health condition or set of behaviors—especially if you can't determine that information by other methods. Surveys have much utility in uncovering what your target population

is already doing, and which needs they find important, and can help you assess important population characteristics like current level of knowledge and perceived self-efficacy regarding self-management.

You can use the results of surveys for many aspects of your program: for example, to develop its health education component. They can also give you a sense of the level of health literacy of your target population. Surveys will also likely be useful in assessing the attitudes of your target population, as well as other stakeholders, of the factors you'd like to address in your program (e.g., level of trust in the health system, self-efficacy related to self-management behaviors in promoting health) and can provide information regarding perceived and structural barriers to promoting self-management and implementing such programs across a particular environment.

Because many surveys can be answered anonymously, participants may be more forthcoming than they might be in an in-person interview. In addition, survey information can be collected relatively quickly and with less effort on the part of survey participants, and can be analyzed relatively quickly after the survey has been administered.

**See pages 22-23 for survey administration considerations.**



## Survey Design Questions

In order to administer a survey, consider the following factors:

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### What questions will we ask?

*Search for standardized survey measures before writing your own questions. Are the questions comprehensible and clear?*

*How will you pilot-test the survey (e.g., through phone or in-person interaction) to make sure they are comprehensible and clear?*

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### How will we deliver the survey?

*Is your target population able and willing to fill out a survey online? Will you send the survey via email, or text a link to a web-based survey?*

*If not, is a mail survey viable?*

*How might participants return it?*

*If the survey requires direct, back-and-forth interaction, how might you work with your organization to promote survey delivery, or use telephone or online communication?*

## **Who will administer the survey? How will they collect data?**

Online tools, such as REDCap and SurveyMonkey, are widely available and can help you design and send surveys out with relative ease. However, these surveys are non-interactive.

*How much time will an interactive survey take, and who will perform it?*

*Will the tools you use to gather and receive data secure all protected health information (PHI)?  
Your survey may require approval from an Institutional Review Board (IRB) if you it is being used for formal research and contains PHI.*

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## **Who will analyze the survey data?**

*What is their level of training and how will they respond to missing or unclear responses?*

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## **How will getting answers to our questions help us in program development?**

*How might we use the information we learn?  
What won't be answered by administering a survey?*



### Process Note

Our formative research reminded us repeatedly of the risk of bias we must avoid—not only from the questions we ask and how we phrase them, but also subconscious assumptions we may reveal regarding which answers we expect to hear and how we interpret them.

For example, our focus groups related to medication adherence revealed wide variation—some patients reported strong adherence to their medication regimens, while others struggled to adhere to schedules, and faced barriers getting medications consistently. Some of these challenges we expected, but the frequency and breadth of patients' access barriers exceeded our expectations.

Closed-ended, leading, or judgmental questions—or follow-up statements—may have prevented us from eliciting these critical data.

Data from surveys are prone to bias, which can lead to misinterpretation of results. The details of these types of bias are beyond the scope of this toolkit—but for example, a poorly-worded question might lead a respondent to say what they think you want to hear, rather than the truth (social desirability bias); or toward an answer the survey suggests is more favorable or less unpleasant (leading questions).

It is worthwhile to conduct some research into the different types of bias, and to interpret your results with these considerations in mind. Consider engaging an expert in survey design, especially if you are using a new survey instrument instead of one proven to work elsewhere—surveys are harder to design and analyze than they look!

Surveys, like all quantitative data collection, can answer questions related to the what and how much of your population and behaviors, but to generate a rich needs assessment, it is best to integrate quantitative data collection with qualitative data collection.

## Qualitative data collection

Qualitative data collection can help you answer the why and how behind your quantitative questions. Qualitative methods—such as focus groups and key informant interviews—can help you answer questions like, “What does healthy behavior mean to your community;” or “What are barriers to healthy behavior change?”

Qualitative data collection also allows you to test working assumptions or preliminary program features such as format, messages, and content. These strategies can be employed at any stage of the needs assessment; depending on what you

already know about your population, you may want to conduct a few focus groups before you design your population-based survey (to inform question generation), or after your survey results have been analyzed (to further investigate results).

You may also employ focus groups or key informant interviews throughout program development to ensure that your program is meeting the needs of your target population.

## Focus groups

Focus groups are guided discussions between interviewers and representatives of the target population that occur in small groups (6-12 people). These discussions can reveal important pieces of information for your program, including the reasoning behind the attitudes your population may have regarding a specific topic, and they can allow you to create a full, rich picture of the target population.

Focus groups can follow different formats—from highly structured and scripted at one end of the spectrum, to fully open-ended, at the other end. When embarking upon the adaptation of this program, we recommend a semi-structured format, where some guiding questions are outlined at the beginning of the focus group, and members are encouraged to share their ideas, opinions of the format and materials, and any concerns they may have about the program content or delivery methods.

## Key informant interviews

Key informant interviews are one-on-one discussions, usually at least semi-guided, with members of the target population or other stakeholders that will help answer any relevant **questions** related to the adaptation of these materials to your context. Key informant interviews can help to both adapt and implement a program.

For example, you may want to interview a few potential peer leaders to get more information specifically related to the peer training aspect of the program. Or, if you're interested in implementing this program in a new context, key informant interviews with administrators or staff can provide insight into anticipated barriers or opportunities for implementation.

The methods you choose depend on the questions you have about your population. For example, if you want to explore in-depth questions, focus groups or key informant interviews may work best. If you need only, or only have time for, surface-level information about a large group of people or patients, use a survey.



# Summarize and present findings to stakeholders

## Data review

The detailed analysis of qualitative and quantitative data for research requires advanced training. But any level of analysis—including tallying survey results or reviewing and summarizing key focus group findings—will be instructive not only to you but all your stakeholders.

Moreover, each of your stakeholders may have different ideas or resources to apply as next steps, based on their own review of the results, that will further help you in adapting the program to your ongoing needs. Your stakeholders will be able to assist you in addressing the needs you've discovered through the process, and leveraging key assets already outlined by the needs assessment.

For further details on formal analysis of data from needs assessments and other evaluative and formative research, see the Evaluation section below.



# 02

## Adapt and Build Your Program

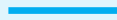
At this stage, you will have a solid understanding of the existing assets and outstanding needs of your target population. These data allow you to begin to adapt programs such as the PHWP, or CDSMP, to fit your needs.

This adaptation stage should use results of the needs assessment, but also incorporate new evidence related to theory-based behavior change. Ideally, the two should interact: at each step in the program adaptation phase, it's a good idea to refer to the results of the needs assessment to make sure that the evidence and strategies you use are helping the program to address those needs.



## **Orienting Questions**

With all your team members, use these questions to inform and situate your work during this phase:



***What behaviors do the patients in our setting already do well?***

***What behaviors do the patients we serve need to adopt, or maintain, in order to self-manage their health?***

***How do patients in this setting learn best?***

***What cultural modifications should we consider?***

***What structure should the program follow?***

# Assemble your team



## PHWP Example

The design of the PHWP was led by a public health expert with experience designing behavior change interventions, in conjunction with physicians from PeakHealth and the lead social worker, as well as administrators and leadership from the practice.

**Your team** is the small group of stakeholders that will be responsible for planning, implementing, and evaluating the program. This team should include not only health experts, but people who understand and represent the community of patients you serve.

## Core team

Ideally, the team has the following core members:

**Program Owner** - This person is responsible for making critical program design and implementation decisions, conducting background research, compiling and collating input from other team members and key informants, and owning the process and deliverables related to design and implementation.



## PHWP Example

The lead PeakHealth social worker served as our main community representative, based on her longstanding engagement with both PeakHealth patients and the East Harlem neighborhood.

**Community Representatives** - These contributors are responsible for informing—if not leading—the program design. They represent the population or setting in which you'll be working, and are responsible for informing feasibility, and championing the program in its setting. They are a critical liaison between patient, provider, program, and system.

**Program Coordinator(s)** - This team member is the executor of decisions, and organizes logistical needs, writes content, and keeps track of tasks and decisions made throughout the adaptation process.

**Specialized Consultant(s)** - This group of contributors are responsible for executing the program materials' design and content; assisting with relevant task completion; and other duties as needed and appropriate.

## Key contributors

The team should also consider bringing on the following key contributors:

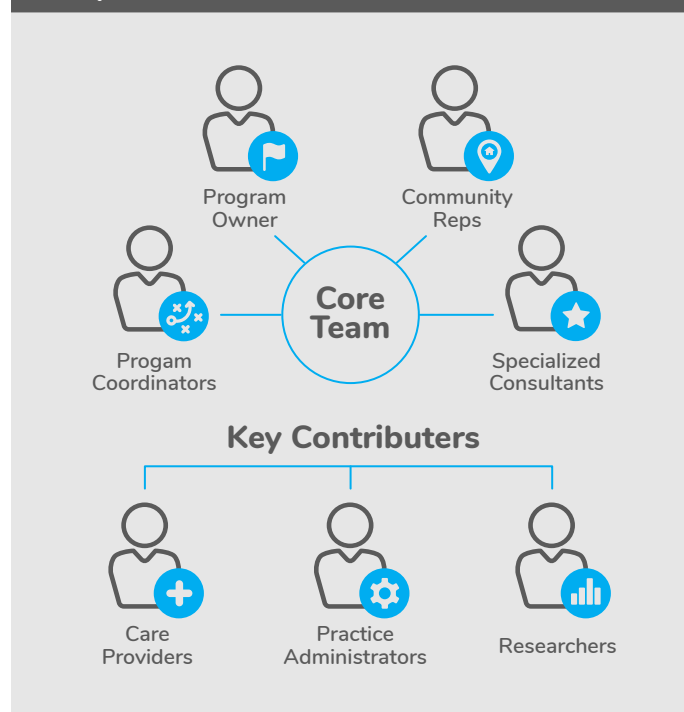


### Process Note

As we planned and executed the intervention, we realized the value in keeping the PeakHealth clinical practice apprised of our plan—both to allow care coordinators to remind patients of the Wellness Program activities, and to help us plan our program around patients' visits and care needs.

**Patients, practice administrators, researchers, and care providers** - These collaborators help inform and guide the decisions made by the core team. They can assist you with logistical support (i.e., coordinating space, reaching out to potential/ participants) as well as higher-level support (advocating for and allocating resources like staff time and help you increase buy-in for your program).

### Sample Team Structure



### PHWP Example

Our core team consisted of three PeakHealth physicians; the program manager/owner; the program coordinator; and the PeakHealth social worker. However, as we identified PeakHealth patients to serve

as peer leaders, they became community representatives as well. Other physicians and researchers joined the team over time, serving as key contributors and content experts.

# Identify key tasks

## Logistics

After selecting your members, decide how best to work together as a team.

Figure out the amount of effort and time per team member it will take to adapt a peer-led self-management program for your specific context.

Communicate clearly about how the adaptation and planning processes will go, and agree together as a team about the primary and secondary goals.

Estimate your anticipated costs: build a program budget, including estimated cost per program participant. Collaborate as needed with partners to identify potential cost savings.

## Workflow

Once you have a strategy for collaboration, consider more specifically how you will adapt and build a program together:

Review all PHWP materials against the needs and assets assessment results. This step will allow you to concretely map the necessary changes, and integrate them into the larger framework of the program.

Outline the adaptation and program implementation steps needed to make these changes, and assign responsibilities and tasks to each team member.

Planning out who will do what both during the program adaptation phase and the program implementation phase will make execution of the program smoother. It will also allow you to anticipate and plan to overcome barriers.





# Get organized and act

## What do I need?

Consider what resources you have to adapt and implement the program, and start moving:

- Set up planning meetings.
- Set agenda and goals for each meeting,
- Create and assign tasks.
- Set deadlines.

## Who do I need?

As a team, ask yourself the following questions:

- Who can help adapt our program?
- Who can inform the adaptation?
- Who will own the decisions?
- Who will implement it?
- Who will support it?



Pamela Allen



# 03

## Design and Assemble Content

Your needs and assets assessment gave you a good sense what to address in your program. The adaptation process revealed what aspects of prior work you must keep, or change, to respond to those needs. In the stage of program design, you'll match up the results from that assessment with specific strategies from previous research to determine the precise content of your program.

If you have outstanding questions after starting to put the program together, you now have key informants from whom you can solicit ongoing feedback. Use the following guide to design and plan the content of your program.

## State your primary goal

This goal may already be apparent—but it will help you focus your program to write it down explicitly. Also list any secondary goals.

For example, if the primary goal is “improve self-management behaviors,” a secondary goal might be “promote a greater sense of community among patients,” and/or “increase access to healthcare at our practice.”

# List behaviors you want participants to change

Be as specific as possible (i.e., instead of “eat more fruits and vegetables,” try “increase vegetable intake from X to Y servings per day”).

In addition to changes in diet and exercise patterns, we recommend including chronic pain management and mental health conditions (depression, anxiety), as the PHWP did. These conditions often occur alongside other chronic conditions like diabetes, hypertension, and obesity, and are well-known barriers to maintaining healthy habits.

Choose a behavior focus not only based on what your resources and the planned length of your program will allow—but also upon the needs and concerns of the community your program serves.

Check your list against the list of topics covered in the PHWP, CDSMP, or other programs you hope to employ. Which behaviors are the same? Which are different?

# Decide on program structure

## Cadence

Once you have decided the behavior content you'd like to focus on, determine the program cadence (e.g., once per week for 1.5 hours in person for the PHWP) and format.

The PHWP structured each session around one self-management topic, to help focus discussion and to aid in guiding the action plan each week. Conversely, the CDSMP reiterates multiple topics each week, to reinforce key lessons through repetition.

## Format

Decide which of these formats your program will follow, or how it might differ. How often will you meet, and for how long? Will you run the program as a research study? If so, be sure to prepare the necessary consent forms, and obtain IRB approval, from your respective departments.

Consider not just what you hope to achieve, but how you will measure it. For instance, will you measure any participant data (e.g., blood pressure, weight, medication adherence) at the start of the program, to compare to a post-program outcome? See "Evaluation" section below for more details.

If you're not sure what structure will be best, it may be helpful to list a few possible structures (e.g., weekly for 1 hour; every other week for 2 hours) and create a list of pros and cons for each option.

The PHWP decided to meet once per week, at the same time each week, for 1.5 hours. We decided on that cadence in order to promote a standard expectation; because it worked well for the staff involved; and with relative confidence that it would not be burdensome for our target population.

If the cadence your program follows is different, edit the materials—content, agenda, and schedule—as indicated.

Decide how many sessions you need to cover all the content and behaviors you'd like to promote.

We recommend, depending on the number of behaviors you want to promote, between **6 and 12 sessions**.

Create a calendar of when you'll present each topic, and how.

How to structure each session?  
(see Appendix for details)

- Does the PHWP structure fit your needs?
- What resources are available?
- Which are necessary?
- Agenda?
- Schedule?
- Calendar of topics?



### Process Note

We originally started with a 6-week program, and extended it to 12 weeks, in order to facilitate increased group cohesion, allow for time to develop trust in the peer leaders, and incorporate time to discuss numerous behavioral health topics, such as dealing with emotions related to health; communicating with family and friends; and engaging with your health provider.

# Review and finalize key content

## Adapting content

Now that you have a list of behaviors and a general outline of what will be covered when and in what format, decide which PHWP (or other model) content you'll keep—and how you will change it.

How does the content need to be adapted for cultural considerations or other context? After you've outlined what needs to be adapted, create any content you'll need to add.

For instance, here are four major buckets of content you'll need to adapt the PHWP program:

### Session Scripts

- What the peer leaders will say to the group
- What they will prompt participants to discuss

### Session presentations

- What information will be presented to the group (either by a peer leader or content expert)
- In what order, and in what format

### Session activities - instructions and worksheets

- What activities the group will do during the session
- What materials these activities will require

### Additional information and content

- Information for participants to take home
- Information they will interact with during each session



# Incorporate PHWP training materials

Does the content fit your needs? If not, make notes of what content you'll need to edit or add. Then, decide on a training plan.

What skills are needed to implement the program?

## Group facilitation

- Leading a discussion
- Managing group dynamics

## Active listening

- Goal setting
- Coaching others to create action plans

## What education do peer leaders need?

- Education related to behavior change (conceptually, theories of change)
- Education related to health conditions



# 04

## Launch Your Program

The exact details of the program you create will depend on all the steps above: identifying your stakeholders' needs, then assembling a core team to connect those needs with existing programs and resources, and lastly designing an intervention to meet those needs.

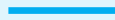
The details of how we delivered our program at Peak Health—and the resources we created for doing so—are separately available on our website. However, some elements crucial to all programs are detailed here.

These include logistical elements such as location, timing, and budget—but more importantly, finding and engaging patients who will lead their peers to better health.



## **Orienting Questions**

With all your team members, use these questions to inform and situate your work during this phase:



***How will participants be recruited?***

***What is your timeline?***

Consider: time to recruit peer leaders, time to train peer leaders, time to recruit participants, and time to run the program.

***How long after recruitment will your program begin?***

***What will the cadence of sessions be (relative to holidays, leaders' availability)?***

***How will you maintain engagement in the program?***

***Will you pay participants?***

***What rate is fair and sustainable?***

***Who needs to be involved,  
besides leaders and participants?***

***Do you have commitment  
from guest speakers?***

***Do you have commitment from  
stakeholder team members?***

***Where will sessions be held?***

***What other materials do you need?***

Consider: food and other in-kind support, audio-visual materials, office supplies (pens, books, whiteboard, markers), exercise equipment, audio-visual materials, office supplies (pens, books, whiteboard, markers), and exercise equipment.

# Recruit peer leaders

## Who should lead?

Before actively recruiting, consider the characteristics you are looking for. Ideally, **leaders** should have a connection to the community they serve—and also be responsible, motivated, and adaptable. They need not have extensive formal education, but should be comfortable reading, writing, and communicating at a high-school level. We have found that patients who currently struggle with chronic illness—yet have made some strides to controlling it, and are actively making more—are often ideal, as they can share their successes and challenges in real time with their peers.



### PHWP Example

We recruited peer leaders through word of mouth, identifying four (later three) patients whose compelling effort to control their own chronic conditions—and affable, non-judgmental personality—made them obvious candidates according to PeakHealth providers and social workers.

## Outreach

Your stakeholder group can advise on how to search. But some helpful places may include churches, senior centers, volunteer organizations, your organization's social media pages, health professionals' advice, and other word of mouth. Consider, before recruiting, how and whether you will pay your peer leaders for their time and effort.

# Train peer leaders

## Logistics

Once you've selected peer leaders, consider how to give them key skills. We have found that small groups over a defined short span work best. Consider 6-10 weeks, perhaps simultaneously with recruit participants. Try to avoid a large gap between peer leader training and the start of the program.

## Content

Training topics may include practice handling difficult situations; facilitating and redirecting a group; action planning; and goal setting. Having peer leaders practice each activity in the program, as well as working with a co-leader, is helpful.

Also pay attention to how your peer leaders work together while training – leaders who are less engaged, less flexible, or more judgmental may not be a good fit for the program.

# Recruit participants

## Outreach

During your needs assessment, you determined the population of patients you will work with. Now consider what recruitment efforts will help you best connect with this target population. Consider not only health clinics you work with, but other local resources, such as senior centers and community-based organizations.

Also consider different outreach strategies—not just e-mails and phone calls, but also announcements at church bulletins, volunteer organizations, or libraries; flyers and newsletters; health professional referrals; and in-person events, such as a **community wellness day**.



### PHWP Example

We recruited patients through a Wellness Day—an event in which we offered yoga, meditation, massage, healthy snacks, and other appealing resources to encourage PeakHealth patients to consider health behavior change.

We recruited attendees to join the subsequent program, and also reached out to patients who PeakHealth social workers and care managers knew were struggling with chronic conditions.



# Schedule and run your program

## When to host

When and where you host your program is vital to the success of your workshop. As always, consider the population that you're working with: working adults may be unavailable during the day, but older adults may travel less at night. Consider, also, ease of commuting, appointment scheduling conflicts, time of year, and weather.

## Implementing

Now that your team has finished the logistical work of researching and planning your program, it's time to move forth and implement your design. Each program will be unique, but the suggestions we provide may be relevant to your setting. In-course corrections (changes in the structure or content of the program) may arise, but try to keep these to a minimum, so you can faithfully test whether the intervention you carefully created is actually successful as it is.

For examples on how to use the accompanying training materials located in the appendix, please refer to the case study.



# 05

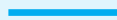
## Evaluate Your Program

As noted above, the complicated science of program evaluation is beyond the scope of this manual. However, several elements are essential to how you assess your work, and how you can make it reach more participants more effectively in the future.



## **Orienting Questions**

With all your team members, use these questions to inform and situate your work during this phase:



**Why are we conducting a program evaluation? What do we want to learn?**

**Who will view the results of this evaluation? (E.g., community leaders, health officials, program directors)**

**How can we collect information timely and accurately? In what format?**

**When is your evaluation deadline?**

**What resources are available to collect the information? (E.g., human resources, medical equipment, physical space, computers, software)**

# Set goals in advance

## Overview

The purpose of any evaluation is to appraise your program relative to the goals you set. These should be decided—with your key stakeholders, and based on participants' needs—well before you begin. This is because they dictate every aspect of planning and delivering the intervention above.

As a consequence, you should know in advance what goals you will evaluate the program on, to see if you hit those targets. For instance, if you decide that helping participants control chronic pain is a key goal, imagine what a realistic endpoint would be for success. And consider how you will measure their level of chronic pain in advance, to see how much difference the program made relative to the start—ideally compared to others who didn't use the program.

## SMART Goals

To be effective in creating and evaluating change, goals should be SMART:<sup>16</sup>



### **Specific, significant, stretching**

In detail, what do you want to do?

---



### **Measurable, meaningful, motivational**

How will you know when you've reached it?

---



### **Agreed upon, attainable, achievable, acceptable, action-oriented**

Is it in your power to accomplish it?

---



### **Realistic, relevant, reasonable, rewarding, results-oriented**

Can you realistically achieve it?

---



### **Time-based, time-bound, timely, tangible, trackable**

When exactly do you want to accomplish it?

---

For instance, evaluating whether participants had “no more pain” would not be a SMART goal, but seeing whether their self-reported pain from zero to 10 changed by an average of two points or more over eight weeks would be. Be sure that the way you measure your goal—whether it’s pain, body mass index, blood pressure, or something else—is careful, consistent, and based on the best scales available. Also be sure to measure it before the program if at all possible.

# Consider different measures

## Fidelity measures: did it happen?

It is tempting to set goals only for the ultimate end results of the program—for example, whether participants' blood pressure or pain level went down. These are called outcome measures. But it's equally important to measure whether you carried out your program according to plan in the first place. This is because—if the program didn't work—you need to know whether the program itself needs repair, or whether you just didn't quite do it right. Measurements of how you carried out a program are called fidelity measures.

### Approaches

There are multiple ways to measure program fidelity. One approach involves mapping out every single step of what is supposed to happen when you launch a care program, and measuring how well that step got done. This is called a care cascade. For a behavior change program involving the steps in this manual, a care cascade fidelity evaluation might include:

- Recruiting peer leaders: How many recruited? How many completed the program?
- Training peer leaders: How many trained? Did the peer leaders understand what you taught them (e.g., through a quick quiz)?
- Recruiting participants: How many recruited? How many completed the program?

- Schedule your Program: How many sessions completed? Which activities (blood pressure checks; counseling lessons; physical exercise happened as planned?
- Run your Program: Did participants understand key messages (e.g., through a quick quiz)? Did they participate (e.g., by completing homework as requested?

The amount of detail in each of these measures—and which ones you select—depend on the resources available to you. But having at least a few will help you not just understand and interpret the outcomes of the program (see below), but also troubleshoot logistical problems going forward. For example, evaluating how well participants understood the messages you shared goes a long way towards understanding why they did or didn't achieve the intended behavior changes.

## Outcome measures: did it work?

It may seem obvious that you must accurately measure the program's intended outcome to evaluate whether it worked. But this process is more complex than it may seem. For instance, you must first ask:

- What exactly is the outcome I want to change (see SMART goals)?
- Do I have the resources and expertise to measure it correctly and consistently? (e.g., proper equipment and training to check blood pressure?)
- Can I measure the result through a survey of participants, or will this be prone to bias (e.g., participants might not remember what they ate or when they exercised, or might tell you what they think you want to hear)?



- How confident do I feel that the result is due to the program itself (e.g., do I want a control group, to see how participants did compared to those who didn't get to use the program)?

The goal of a behavior change program for health, ultimately, involves multiple steps. First, the program should empower participants to change their beliefs and attitude. This shift then changes their health behavior. And the health behavior starts to change health outcomes, such as lower blood pressure or a healthier body mass index. Those changes, over time, prevent diseases such as diabetes or strokes—which ultimately help people live longer lives.

Unfortunately, these longer-term changes, such as prevention of diseases like diabetes or heart attacks, take many years to emerge. Also, since no program works for everyone—and these diseases are not entirely within our control—you would need your program to treat many, many people and then track them for a long time to evaluate whether the program actually prevents those diseases. Unless you have a large research budget, a long span of time, and an expert scientific team, that type of **evaluation** is probably not realistic.



### PHWP Example

We designed an evaluation plan in discussion with our stakeholders before launching the program. This plan involved mixed methods that incorporated physical quantitative data as well as qualitative interviews. It also incorporated both fidelity and outcome data.

Instead, your outcome evaluation should probably focus on short-term changes, at least at first. For instance, do participants report changes in their behavior over the weeks the program went on? Were they able to keep up those changes in the months afterwards? Did their blood pressure go down and stay down during that time? If your program is impacting those outcomes, it is likely making some impact on participants' long-term health, even if you can't prove that directly.

This type of evaluation can take many forms. But two key types of outcome measures are detailed below.

# Select your tools

## Quantitative tools

Measuring numbers—such as blood pressure results—for participants in a program is a compelling way to evaluate its impact. These numerical results are called **quantitative outcomes**.

A few examples of key quantitative outcomes (e.g., via physical surveys, chart reviews, financial audits)—and what they assess, are listed below.



### PHWP Example

Specifically, we measured each participant’s blood pressure (three separate measurements), weight, medication adherence, depression score, and other quantitative results before and after the study.

### Sample Quantitative Outcomes

Category	E.g. outcomes	Impact assessed
<b>Disease control</b>	Hemoglobin A1c levels	Diabetes
	Blood pressure values	Hypertension
	Body mass index	Obesity, malnutrition
	HDL, LDL cholesterol levels	Cardiovascular health
<b>Health care usage and cost</b>	Cost of program per patient	Investment
	Outpatient cost savings	Actual impact
	Projected cost savings	Estimated impact
	Cost for hospitalizations and ER visits	—
	Hospital and ER utilization rates	—
<b>Self-mgmt support</b>	Enrollment rate	—
	Attendance rate	—
	Completion rate	—

## Qualitative tools

However, numbers don’t tell the whole story, especially when the goal of the program is to change attitudes, beliefs, and behaviors. Just because someone with high blood pressure didn’t change their numbers immediately doesn’t mean the program didn’t help them get on that path.

And even a person whose attitude didn't change because of the program can tell you a lot about why not—if you take the time to speak with them.

The other main way to evaluate a program is through **qualitative outcomes**—interviews, discussions, and other descriptions of what happened in the program—how people experienced it—and how it may have changed their views, beliefs, or action. Contrary to some opinions, qualitative work is not “softer” than a series of numbers. Rather, it tells a story the numbers cannot—to help you see why and how a program impacted participants.

A few examples of key qualitative outcomes (e.g., via key informant interviews, focus groups, questionnaires)—and what they assess, are listed below.



**PHWP Example**

Separately, we conducted an in-depth interview with each of fifteen participants, leaders, and staff members associated with the program after it ended. We also tracked program enrollment, attendance, and completion over time. See the program case study for further details.

**Sample Qualitative Outcomes**

Category	E.g. outcomes	Impact assessed
<b>Program interest and experience</b>	Why participants joined	—
	What they expected	—
	What they found	—
<b>Health behaviors and beliefs</b>	Causes of chronic diseases	—
	Experience with health system	—
	Challenges with behavior changes	—
	Self-confidence to make a change	—
<b>Feedback and next steps</b>	What worked well or poorly	—
	How program made participants feel	—
	What should change	—
	What is most important to keep	—

## Summary of tools

Both types of outcomes are crucial to carefully evaluating a program, and each one complements the other. An evaluation that uses both, if possible, is ideal. This approach is called a mixed-methods evaluation. Becoming an expert in either one can take years of expertise. But the tools above can give you a solid sense of what worked and what needs improvement.

The evaluation process—like every step in this guide—will help make your program stronger, broader, and more sustainable over time.

The process of consistently, iteratively planning a program—studying how to make it work—doing it—and then evaluating and adjusting (sometimes called the PDSA cycle) is crucial to sustain.<sup>17</sup> By following and repeating this cycle, you can develop and refine a behavior change program that addresses and impacts the unique short- and long-term health needs of your own community.

# Summary

Managing one's health while living with chronic conditions is not easy. But years of research have shown that programs that help people to help each other to understand and control these conditions have an impact.

These programs take many different forms. But all involve a few key steps—and all have adapted these steps to fit the community they serve.

We hope that this guide gives you both the materials to build such a program, and the ideas and strategies to make it your own. As with all health interventions, your effort to build a chronic disease behavior change program will involve trial and error. That's why—after you adapt, design, and launch your program—you'll need to evaluate its impact. Then you can make changes to make the program stronger, as you and your community partners repeat that cycle anew.



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