Building Community-Based Chronic Disease Interventions: A Handbook

Developed by Primary Care Development Corporation (PCDC) in cooperation with the North Country Health Information Partnership, a program of the Fort Drum Regional Health Planning Organization

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ABOUT PCDC

The Primary Care Development Corporation (PCDC; www.pcdc.org) is a nonprofit organization dedicated to transforming and expanding primary care in underserved communities to improve health outcomes, reduce healthcare costs and disparities. Our programs enhance access to primary care by offering flexible financing to build and modernize facilities, providing coaching and training to strengthen care delivery, and leading policy initiatives.

Since 1993, PCDC has partnered with more than 500 primary care organizations throughout the U.S. to adopt a patient-centered model of care that maximizes patient access, meaningful use of health IT, care coordination and patient experience, as well as build community health resilience through disaster preparedness and business continuity planning. Certified as a Community Development Financial Institution (CDFI) by the U.S. Treasury, PCDC has invested more than $390 million in over 95 primary care capital projects. This investment has improved 785,000 square feet of space and created more than 4,000 jobs in low-income communities.

PCDC’s Performance Improvement Practice has helped more than 5,000 healthcare staff redesign workflows and processes, adopt new technologies such as electronic health records, to enhance the delivery of primary care services for millions of patients. PCDC’s Performance Improvement unit is composed of 20 professionals with more than 90 years of collective experience in managing, implementing and evaluating quality improvement initiatives, including chronic disease management, medical home transformation, health IT optimization and primary care redesign.

Contact Us:
For more information about PCDC’s Program and Services please visit our website at www.pcdc.org or call us at 212-437-3900.
ABOUT FDRHPO

FDRHPO or Fort Drum Regional Health Planning Organization is an agency that strengthens the North Country Healthcare System for Fort Drum Soldiers, their Families and the surrounding civilian community. FDRHPO connects the Military Treatment Facility with the regional healthcare system. FDRHPO does not provide services; rather our role is to evaluate, plan and strengthen the link between Fort Drum community members and quality health care in Northern NY.

Our Mission

Initiated and supported by then Congressman John M. McHugh, FDRHPO originated from a Department of Defense 721 pilot program for healthcare delivery. The mission of FDRHPO is to analyze the existing healthcare system available to Fort Drum Soldiers, their Families, and the surrounding civilian community, identify gaps and then leverage additional medical resources.

To enhance and expand healthcare resources for the growing Fort Drum community, FDRHPO created partnerships with regional healthcare institutions. The result is a strengthened, more adaptive Healthcare System that is still in use today.

Our Goals

- Identify the healthcare needs of Fort Drum and the surrounding community
- Develop a plan to address and support the healthcare needs of the entire community, including Fort Drum
- Foster the collection and exchange of information to promote health through coordinated area-wide health services and programs
- Further such purposes in coordination with federal, state, and county governments, the military and local health care providers, agencies and consumers and in accordance with supporting the mission of the U.S. military; and
- Leverage resources to further the stated objectives

Contact Us:
For more information about FDRHPO’s Program and Services please visit our website at [www.fdrhpo.org](http://www.fdrhpo.org) or call us at (315) 755-2020.
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Chapter 1

Defining Your Project

Introduction
As more healthcare providers use Electronic Health Records and achieve compliance with quality standards such as Patient Centered Medical Home, policy makers and planners have expanded the focus beyond individual practices to include whole communities of healthcare providers, encouraging these providers to work together to treat “the whole patient” and to achieve the “triple aim” of improving the experience of care, improving the health of populations, and reducing per capita costs of health care. ¹ Recent policy trends towards Accountable Care Organizations ² and Health Homes ³ indicate this emphasis on coordinated care between disparate providers, and suggest a movement beyond “patient centered medical homes” toward one of “patient-centered medical neighborhoods.”

Furthermore, efforts to control costs have targeted chronic diseases, as these diseases lead to such a large share of overall healthcare spending.⁴

These policy developments encourage stakeholders in communities in New York and across the country to develop community-wide projects to achieve the “triple aim” goals relative to chronic diseases.

This handbook offers an approach to doing so. We describe the components of an intervention, and provide tools for working through each step of the process, and identify questions to ask at each stage, along with challenges you and your community are likely to face as you develop and implement a chronic disease intervention.

Getting Started
Before designing an intervention, you may want to ensure that you have certain prerequisites in place. These include, for example:

- Resources (including staff or at least a staffing plan) to support developing a project within your organization
- Relationships with health care providers and agencies within your community
- Funding to apply to the project, or ideas on potential funding sources
- A list of stakeholders in your organization or your healthcare community

² https://www.cms.gov/ACO/
³ http://www.health.ny.gov/health_care/medicaid/program/medicaid_health_homes/
⁴ http://healthaffairs.org/blog/2010/02/19/chronic-conditions-now-drive-medicare-spending-increases/
● A determination of who “owns” the project. That is, who is ultimately responsible for the design and oversight of the project? Will it be you personally, someone else at your organization, another organization, or a partnership of two or more organizations? (The remainder of this handbook is aimed at the organization who “owns” the project.5)

Methods for establishing these prerequisites are beyond the scope of this handbook, but once you feel they are in place, you are ready to begin designing the intervention.

Identifying Potential Chronic Diseases
A first step in designing a Chronic Disease Intervention is to select the chronic disease or diseases that you would like the project to affect. Some basic considerations in selecting the disease include these factors:

● Prevalence among the patient population in your community6
● Costs associated with treating patients with this disease
● Performance relative to state or national averages (e.g., mortality and hospitalization rates, clinical outcomes, survey data on patient quality of life, etc.)
● Interest in intervening in the disease from partners, including public and private agencies and funders

Looking beyond the basics, you may also consider a project that will have an impact on patients with a chronic disease and certain comorbidities, due to the complexities and costs associated with treating those patients (for example, HIV patients who also suffer from schizophrenia, diabetics who also have cerebral palsy, etc.)

A variety of reference sources are available to help you determine prevalence of diseases and the performance relative to those diseases in your community. These include, for example:

● Local public health departments
● State public health. In New York, some useful source include:
  ○ Statewide Planning and Research Cooperative System (SPARCS)7
  ○ Community Health Assessment Clearinghouse8
  ○ County Health Assessment Indicators (CHAI)9

5 Hereafter, the word “you” is shorthand for referring to “your organization” or “your project team.”
6 For purposes of discussion, the word “community” refers broadly to the geographic area your project will affect. A more formal term for this concept is “Care Coordination Zone” (CCZ).
7 http://www.health.ny.gov/statistics/sparcs/
• National public health agencies
  ○ Department of Health and Human Services
  ○ Centers for Medicare and Medicaid Services (CMS)
  ○ Center for Disease Control and Prevention (CDC)\textsuperscript{10} and its WONDER program\textsuperscript{11}
  ○ Agency for Healthcare Quality and Research (AHRQ)\textsuperscript{12}

• Private foundations and research organizations
  ○ “America’s Health Rankings” from United Health Foundation\textsuperscript{13}
  ○ “State Health Facts” from the Henry J. Kaiser Family Foundation\textsuperscript{14}
  ○ “Kids Count” data center from the Annie E. Casey Foundation\textsuperscript{15}
  ○ “County Health Rankings” from the Robert Wood Johnson Foundation\textsuperscript{16}

To determine prevalence in your community, you may also have access to disease registries or detailed population health data specific to your community, including data stored by a Health Information Exchange (HIE)/Regional Health Information Organization (RHIO). If your community does not have a fully operable RHIO, you may choose to “pre-assess” your healthcare providers and ask them to report individually on those diseases that are “clinically important,” as measured by percentage of encounters, number of patients with each condition, or billing associated with each condition. (Which specific measure you select is less important than using the same measure for each stakeholder responding to your inquiry. That is, if you are trying to determine the “importance” of a disease within your community, be sure to use the same measure of “importance” for each stakeholder.) Keep in mind that this process may be onerous for those stakeholders who do not have an Electronic Health Record (EHR), and may be onerous even for those who do, depending on the reporting capabilities of their EHRs, and their familiarity with those capabilities.

In addition to studying prevalence and performance, you may want to consider the costs associated with specific chronic diseases. Sources include:

• Medicare and Medicaid spending data
• CDC’s Chronic Disease Cost Calculator\textsuperscript{17}

\textsuperscript{9} http://www.health.ny.gov/statistics/chac/chai/index.htm
\textsuperscript{10} http://www.cdc.gov/chronicdisease/resources/publications/AAG/chronic.htm
\textsuperscript{11} http://wonder.cdc.gov/
\textsuperscript{12} http://qualityindicators.ahrq.gov/Modules/iqi_overview.aspx
\textsuperscript{13} http://www.americashealthrankings.org/
\textsuperscript{14} http://www.statehealthfacts.org/
\textsuperscript{15} http://datacenter.kidscount.org/
\textsuperscript{16} http://www.countyhealthrankings.org/
By using these and other sources to research conditions in your community, region, or state, and compare costs, prevalence, and performance relative to others, you can identify chronic diseases or other conditions for which an intervention is most appropriate.

For example, a review of New York State’s Chronic Health Assessment Indicators data shows that Lewis County, NY, is in the top quartile of performance for some indicators (mortality rate for Congestive Heart Failure), but in the bottom quartile for several others (e.g., hospitalization rates for Coronary Heart Disease and Cardiovascular Disease). This suggests an opportunity for further inquiry.

Reviewing available data sources to identify which chronic disease indicators show disparities between the performance in your community as compared to performance state-wide or nationally will enable to you to make a list of potential areas for intervention.

Beyond the data, you may also choose to have conversations with others about what disease conditions they have identified as a priority for your state, region, or community. As suggested above, these may include state and local health care officials, healthcare membership organizations in your community, funders you have worked with in the past or would like to work with, board members of your organization, and patients or patient organizations within your community. Perhaps there are other organizations working on this disease in your community. They can provide additional information, serve as a partner, or perhaps help you discover that their organization is more suited than yours to take on a specific disease intervention (saving everyone a lot of work and frustration). As you collect ideas from these parties, you can use the resources described above to research the data behind the ideas, and further refine the possible “candidate conditions” your project will focus on.

Refining the Possibilities

Once you have reviewed the available data regarding chronic conditions in your area and made a list of potential chronic diseases to focus on, you can reach out to stakeholders in your community to determine which disease (and, tentatively, which specific indicators related to that disease) you would like your project

17 http://www.cdc.gov/chronicdisease/resources/calculator/faq.htm
18 http://www.hcup-us.ahrq.gov/
19 http://healthcarecostmonitor.thehastingscenter.org/kimberlyswartz/projected-costs-of-chronic-diseases/
to affect. The availability of hard data will allow discussions with these stakeholders that are concrete and specific. As suggested above, stakeholders in your community may include:

- Public health officials (state and local)
- Healthcare-related membership organizations such as independent physician organizations, primary care associations, local medical societies, EHR user groups, etc. Speaking with providers whose work is directly connected to candidate conditions may provide particular value (e.g., if you are considering an intervention related to diabetes, a local endocrinologist is likely to be a helpful resource)
- Hospital executives and boards in your community
- Public and private funders who have expressed an interest in your community and/or candidate diseases, or who you think would be interested in supporting your community. This may include payers who have an interest in reducing cost and improving quality.
- Your organization’s board members and staff
- Patient advocacy groups in your community, particularly any related to the diseases you’ve identified as candidates for your project

By meeting with these stakeholders and discussing the candidate diseases along with the related data, you have the opportunity to obtain buy-in from your community very early in the process, and to identify and respond to doubts, concerns, challenges, or other factors that you may not have discovered alone. Addressing these concerns in the community at this stage, before the disease has been selected, should help avert challenges to the selection and underlying data later.

Your discussions will likely yield opportunities for further research:

- Are there problems (perceived or actual) with the data you’ve used?
- Are there conditions you had not previously considered that the stakeholders feel is a priority in the community? What does the data say about those conditions?
- What specific indicators related to a disease are you most likely to have an impact on? Is the perception among stakeholders that affecting those indicators is feasible, difficult, or impossible?

**Considering an Intervention**

At this stage, the primary focus is on selecting a condition, but that process cannot be entirely separated from considering the type of intervention your project will provide. To ensure your project is feasible and can have some impact on the selected condition, you can use this period of research and discussion to develop rough ideas of the kind of intervention you would like to make. However, it’s most likely too soon to commit to a specific intervention plan: that will require its own planning process, as described later in this document.
During your discussions, stakeholders are likely to share their ideas for an intervention. In fact, you may want to encourage this type of discussion (e.g., “So how do you think we can have an impact on this condition?”) This is a good opportunity to capture these ideas for further discussion and research, so that once you have selected a disease, you have a head start on designing the intervention. Your payers and potential funders, in particular, are likely to have some insight into intervention approaches.

Additionally, you can also investigate potential interventions for your candidate diseases. By reviewing medical literature, public health journals, and other resources, you can begin to see what types of interventions have been shown to work, and consider in broad terms what would be feasible and beneficial for your community. Some resources include:

- Public health journals, such as “Health Affairs”
- Pubmed, the online database of the National Center for Biotechnology Information23
- Medical journals and professional societies, especially those directly related to the chronic diseases you are considering (e.g., “Diabetes,” and the American Diabetes Association)

Some types of intervention to consider may include:

- Increasing emphasis on care coordination (between primary care, specialists, and hospitals, for example)
- Leveraging health information technology (HIT) for population management and risk stratification
- Implementing new care management activities, for example:
  - pre-visit “huddles”
  - group visits
  - the formal use of “care teams” to ensure continuity of care and a whole-patient orientation
  - the use of a “care manager” or “care navigator” who help patients follow-through on their care

It’s important to note that this particular phase of the process is likely to be non-linear: through your discussions and research, you will be exposed to a lot of ideas, suggestions, questions, and challenges. The challenge for you in organizing the project will be to filter the information you collect and store it for later use. For example, some stakeholders in your community may push to define the intervention right as you are speaking with them. But, since the process of designing the intervention will involve many stakeholders, you’ll be unable to commit to a specific intervention during the discussion. By clearly explaining that and capturing any suggestions, you can keep your process organized while still gaining the benefit of discussing it.

with a variety of people. (The process of fully specifying the intervention will occur after you have made selected the chronic disease, and is discussed later in this handbook.)

**Finalizing the Disease Selection**

Refining your selection and formulating ideas for potential interventions could take a month, or it could happen in a few days. That depends on the time you have available to make a decision and the degree to which you want to involve your stakeholders in the selection. Sometime, you may have a desire to reach out to many stakeholders, but the realities of a funding opportunity timeline may require you to accelerate the process greatly. (In cases where these discussions happen very quickly and you do not have time to reach out to everyone you would have liked to, you may choose to reach out to them as soon as you are able, so that you can inform them of your selection and rationale and respond to any concerns before the project’s implementation begins.)

Once you’ve met with a variety of stakeholders and performed additional research, it’s time to review all feedback and data, and decide the chronic disease your project will involve. Some final questions to consider:

- Is there consensus in the community that an intervention would be beneficial for this disease?
- Are we likely to be able to have an impact on certain indicators? Have we identified some of those indicators?
- Do we have a rough idea of the kinds of interventions we might make?
- Can I clearly explain to anyone who asks why we selected this disease?

Upon selecting the disease, you can focus on designing an intervention specific to that disease. The next step in that process is setting goals.

**Setting Goals**

To create and implement an effective intervention, it is of critical importance to clearly define what you’d like to accomplish. You can do so by setting goals.

In constructing large-scale, long-term project such as a chronic disease intervention, it may be helpful to have a “hierarchy of goals” to guide you, the project team, and your participating stakeholders. We have found a hierarchy that includes these three components to be helpful:

- **Mission Statement.** The overarching purpose of your project.
- **Goals.** The specific items you will achieve that are consistent with your mission statement.
- **Objectives or Tasks.** The steps you will take to achieve your goals.

Definitions for all three, and processes for establishing them, are below.
Mission Statement

A mission statement is an overarching goal that succinctly describes what you are trying to achieve. It is the foundation on which other, smaller goals are built. A project should have just one mission statement. The mission statement should be general enough to allow for flexibility, but specific enough to be meaningful and communicate the essence of your project to your stakeholders and to outsiders. It may include something about what you want to have an impact on, and how you want to make that impact. In other words, the mission statement helps set the scope of the project.

A good mission statement can serve as a filter almost any idea for your project, and help you determine whether that idea is within your mission and outside of it. This will be invaluable during the planning stages of your intervention (when you are soliciting and receiving feedback from diverse stakeholders), and during the implementation of your project, when your project encounters complexity and you want to ensure that your work remains consistent with the mission of the project.

A flawed mission statement will be too broad to be meaningful, and will not express anything definitive about the scope of the project. For example, “Our project’s mission is to improve health” is too general, as it suggests the project could include almost any activity as long as it might improve health. This statement does not help others truly understand what you are hoping to accomplish, nor does it help you effectively manage your project.

By contrast, a more useful mission statement could be something like, “Our project’s mission is to improve clinical outcomes for our diabetic patients through better coordination of care.” That statement concisely describes your project, and sets a scope for it. Because of its ability to provide you with a “filter,” a mission statement can have a profound impact on the daily operations of a project. For instance, to continue with this example mission statement, if someone suggests a potential activity for the project that has nothing to do with diabetic patients and coordination of care, then you can easily determine that it is not consistent with the mission of the project, and therefore should not be pursued.

Goals

A goal is a statement of something specific that you would like your project to accomplish. As mentioned above, it should be relevant to your project’s mission statement. Goals will guide your planning process, focus the work you and your participating stakeholders perform on the project, and will serve as the means by which you measure the success of your project.

In setting goals, a useful concept to keep in mind is the framework of “S.M.A.R.T.” goals. This mnemonic acronym suggests that every goal for your project have these attributes:

- Specific
- Measurable
- Attainable
- Relevant

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● **Time-bound**

A goal should be **specific**, describing what should be done. In this specificity, the goal refines the mission statement into discrete parts. In keeping with the example mission statement described above, your care coordination project might include a specific goal such as “Improve care coordination by establishing written agreements between primary care providers and specialists describing the process for referrals.” A less specific goal is likely to be less helpful at this level of the goals hierarchy. For example, the statement “Improve care coordination” is a good component of a mission statement, but is not specific enough to inform project planning activities or guide your work, and therefore is not a useful goal.

It’s also helpful to avoid being too specific with your goals at this level. The intent of the goals is to **guide** the work, not to specify each and every aspect of the work. (That is something you can do through the use of defining objectives, tasks, and a project plan.) So, a statement like “Get new fax machines” is likely too specific to be useful as a goal and probably is more suitable as a task in a project plan.25

A goal should be **measurable**. That is, you should be able to have a way to determine whether you are meeting the goal or not. If your goal is to improve continuity of care between primary care and specialty providers, how will you measure that? Goals such as “improve health” or “improve care coordination” are not measurable unless you stipulate how you will measure it. But, specific goals also tend towards measurability: Our earlier example -- “Improve care coordination by establishing written agreements between primary care providers and specialists describing the process for referrals” -- suggests several potential measures. You may identify “process measures” such as the number of referral agreements that are in place between the providers, the number of specialty reports returned to the primary care provider, etc., and “outcome measures” (aka “clinical measures”) such as the HgA1C levels of diabetic patients who were affected by the care coordination aspects of the project. (The full process of defining measures is described elsewhere in this handbook.)

A goal should be **attainable**. In setting goals for your project, it is important to keep in mind what is possible given the resources (staff, money, time) you have to achieve it. There are many goals that are specific and measurable, but not attainable. For example, “Get every diabetic patient to stop smoking” is both specific and measurable, but unlikely to be attainable, especially in any time-limited project. By contrast, a goal such as “offer smoking cessation counseling to 90% of applicable diabetic patients” is something more likely to be within the control of your participating stakeholders, and therefore more likely to be attainable. Setting unattainable goals will cause you to waste resources that could better be spent on achieving other attainable goals.

A goal should be **relevant** to your organization and to your mission statement. As mentioned above, a well-formed mission statement can serve as an excellent filter for proposed goals. For each goal, ask, “Is this

25 It’s worth noting that the line between goals and objectives/tasks is context-sensitive. In an environment (such as a developing country) where fax machines are rare but could greatly improve coordination of care, “Get new fax machines to facilitate communication among providers” could be a perfectly appropriate and useful goal, particularly if getting the fax machines is itself a complex process.
relevant to what we’re trying to do?” In a project such as a chronic disease intervention, the selected disease itself often helps to determine relevancy. For example, you may in a planning session and someone suggests that cancer patients also require some intervention, and they will suggest one. They may very well be right, but your mission statement enables you to stay focused on diabetic care, and reframe the discussion accordingly. Relevance, like specificity, is context-dependent, and will require judgment to determine, which is why having a clear mission statement is so important.

Finally, goals should be time-bound. This simply means that goals should have a timeframe associated with them. Setting a timeframe for all goals helps plan and prioritize work, and helps motivate stakeholders to achieve them. Most chronic disease intervention projects will have a built-in end date based on the funder stipulations, but within the overall project, setting a timeline for each goal remains important; otherwise, stakeholders may leave all work until the end of the project, only to find they no longer have the time to complete them all.

Although it is not explicitly included in the “SMART” framework, goals should also have a priority to assist in project planning and ongoing management.

Objectives or Tasks
Although the words “goal” and “objective” are often used interchangeably, we find it useful to distinguish between them as a means of focusing conversations about goals. As mentioned above, a “goal” is a statement of what you hope your project will accomplish, and correlates directly to your mission statement. An “objective” is a task required to achieve your goal. For example, to continuing with our “fax machine” example from above, “Improve continuity of care” is a goal; “Get new fax machines” is an objective to achieve that goal.

The distinction is important: if you set “get new fax machines” as a goal, and then buy fax machines for your participants, you’ve achieved your goal, but you haven’t necessarily done anything to improve coordination of care. Similarly, perhaps a stakeholder will suggest a goal should be “Implement electronic health records at all specialty practices.” It may be helpful to keep in mind that although implementing an EHR may be an admirable effort with many side benefits, the implementation by itself will not improve coordination of care. Therefore, you may have chosen to state the goal as, “Improve coordination of care through the exchange of electronic health information,” and an objective to achieve that goal: “Implement electronic health records with the capability of exchange data.” This objective would be alongside others such as “Train providers on using the EHR to order referrals.”

Because the term “objectives” is often used interchangeably with “goal,” you may care to facilitate conversations without the use of the word “objectives,” and call them “tasks” instead (e.g., when someone suggests a goal of getting new fax machines).

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26 For purposes of illustrating the distinction between a goal and an objective, consider the worker at a fast food restaurant whose job is to fill the central napkin dispensers. Often, the napkin dispenser is stuffed so full of napkins, it is difficult for the customer to retrieve one without ripping several and trying again in frustration. In these cases, the worker has confused his objective (“Fill the napkin dispenser”) with his goal (“Distribute napkins to customers”).
From a process perspective, you will likely be setting objectives after you set your goals. They are described together here to provide an overall picture of the goals hierarchy.

**Involving Stakeholders in Setting Goals**

With a clear understanding of the goals hierarchy, you can engage your community stakeholders to establish a mission statement and set of goals for the project.

During the earlier phase of selecting the chronic disease, you identified and met with stakeholders individually. To set goals for the project, you may choose to gather some or all of them together in a strategic planning session. Note that this group will not necessarily be your eventual governance committee; rather, you are bringing them together to incorporate a broad perspective into your goals, and -- most importantly -- to achieve community buy-in to your project.

Based on your own knowledge of your stakeholders, you can select all of them, or a subset of them, to participate. We recommend that at least one representative from each type of stakeholder be involved in goals setting: e.g., this would commonly include at least one primary care provider, a relevant specialist, a hospital administrator and/or provider, and a representative from public health. If you project making use of a HIE, representatives from the HIE/RHIO may help to ground the discussion in reality. Anyone with experience in gathering data for research or for public health may also be a useful resource for discussing the “measurable” aspects of the goals that the group proposes.

Again, the purpose for the session is to gather many perspectives and a candidate list of goals. (The purpose is not to define a final list of goals. You can do that within the context of your organization, project team, or formal project governance structure later.)

The agenda for the session can be straightforward:

- Introduce the project and the stakeholders in the room
- Discuss the reason the chronic disease was selected to motivate them toward taking action. (Many stakeholders should already be aware from participating in the selection.)
- Discuss the framework for setting goals (mission statement, SMART goals, goals vs. objectives, the list is not final, etc.)
- Establish the mission statement
- Develop a tentative list of goals and measures
- Establish next steps and a feedback loop

The goals you develop as a group should be specific in nature, but general enough to allow for variations specific to each stakeholder. For example, the group may decide that every participating primary care
provider should have a goal of adopting evidence-based guidelines for the care of diabetes. However, specifying exactly which guidelines is highly likely to cause resistance among providers, particularly those not present at this session.

In this session, it probably will not be fruitful to have an extremely detailed conversation about measures. Rather, the purpose is to keep participants focused on the idea of measurable goals, and to get some ideas for measures, which you can refine later (as described elsewhere in this handbook). Through your previous research, you will have some idea of measures relevant to the disease (for example, the measures that the state department of health tracks), and you can share these with the group, who may not be as familiar with them.

Depending on the scope of the project you have in mind, a well-facilitated goals planning session could take between 2-3 hours. We recommend at the end of the session, you clearly state next steps for the group, including how you will communicate back to them the refined list of goals and measures, and what action, if any, is required of them as a group or as individuals.

With this tentative list of goals, you can then filter them, and according to a process of your choosing (collaborative or not), develop the final list of project-wide goals, distributing them back to the group for review.

Now that you have the mission statement, goals, and a tentative list of measures (and perhaps some objectives), you are ready to fully define the intervention. The first step in that process is to more clearly define the measures of success.

**Measures**

Now that you have established a mission statement and some broad goals relating to the chronic disease project, the next step is to consider the specific impact you want the project to have, and how to measure that impact. By measuring the impact, you can determine whether your chosen interventions are successful or not.

Some measures are specific to individual patient’s health (such as blood pressure, cholesterol, etc.) Others measure a population’s health (e.g., mortality rate, cost). This section will help you in identifying the individual and population measures appropriate for your project.

**Note:** The attached tool, “Aligning Chronic Disease with Achievement Measures,” can help you explore two areas of a disease’s impact – (1) patient’s quality of life, and (2) public health – and select measures of both.

- **Quality of Life measures** indicate how the chronic disease is affecting that patient. E.g.,
  - Pain Assessment
  - Physical function
  - Behavioral health
  - Other disease specific symptoms

- **Public Health measures** indicate how the disease affects the population at large. E.g.,
- Prevalence of the disease
- Costly procedures associated with the disease
- Cost effectiveness
- Re-hospitalization rates
- Morbidity and mortality rates

By identifying appropriate measures, you can monitor whether and how the interventions will improve the quality of care, cost effectiveness, and patient experience of care for the chronic disease in your community.
Chapter 2

Preparing for Change

Having fully defined your intervention project, you can now work to prepare your organization and the participating organizations to implement it.

Preparing Your Organization

Generally speaking, the steps involved in preparing your organization to oversee and support a chronic disease intervention project are:

- Assessing and obtaining resources
- Assembling and orienting your team
- Establishing the team’s principles of operation

Assessing and Obtaining Resources

The resources that your organization will likely need to support your project include:

- Adequate staff
- A budget
- An information technology infrastructure to support collaboration
- Optional: Third-party technical assistance providers (consultants) or other organizations

Assessing the status of each of these will enable you to understand gaps in your needs, fill those gaps, and move forward with a solid foundation in place.

Assess your staff. To determine whether you have the people and skills required to support the implementation of the project and to deliver the support you wish to provide to your participants, you can assess your existing staff capabilities. Questions to answer include:

- Based on the design of your intervention (see “Designing Your Intervention” above), what skills, knowledge, and experience will staff require to successfully support the project? This may include expertise in these areas, among others:
  - Clinical process, particularly in the area of the intervention

27 This section assumes that your organization will directly support the project through a team. Alternatively, if your organization is hiring a third-party organization to provide nearly all services related to the project and your role is simply to manage that organization, much of this section may not apply.
○ Project management
○ “Coaching” or other experience supporting practices in achieving goals
○ Information technology (IT), especially in the use of EHRs or reporting systems
○ Project evaluation (i.e., the ability to track status against project measures and determine whether the project is successful or not)
○ Financial planning, especially for complex, long-term, resource-intensive projects and those connected to incentives payments or other changes related to billing operations

- Which staff members have the skills, knowledge, and experience relevant to the project and its interventions?
- Do the qualified staff members have the time to dedicate to this project? If so, what other competing priorities do they have that may periodically interfere with their ability to work on the project during its timespan, especially the expected high-intensity periods?

To answer these questions, you may find it helpful to create a written “asset map,” a matrix of project areas (as described above), and populate it with the names of staff members have the required skills, knowledge, and experience. This process will identify gaps in your organization relative to the requirements of the project. Once you’ve identified the gaps, you can determine whether the best method to eliminate those gaps is to train existing staff, hire new staff, engage a consultant to provide technical assistance, or revise the scope of the project to eliminate that need. (Note: You may want to involve the staff members themselves in this process, as they may have skills or prior relevant experience that you’re not aware of.)

If you elect to hire new staff, be sure to align job postings with the specific skills you need to complete the project. If you’ve already identified some staff who will work on the project, we recommend including those team members in interviews of job candidates, as the ability of team members to work together effectively is likely to be one of those most critical factors in whether your project is successful or not.

**Third-party Technical Assistance.** If your assessment of your staff reveals that you have gaps in your ability to service all aspects of your project, and you are unable to fill those gaps through training or new hires, then you may consider hiring a consultant to fill those gaps. Although the complete process for identifying and retaining a consultant is beyond the scope of this handbook, in general some activities related to this process include:

- Creating a Request for Proposal (RFP) that outlines your project and describes the services you would like the consultant to provide.
- Evaluating the proposals, being sure to obtain the prospective consultants’ answers to these questions (among many others):

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28 An “Asset Map” tool is included in this handbook.
○ What skills or experience do you have with projects like this one?

○ What references can you provide for past work?

○ How much will it cost, and will the contract be deliverables-based or based on time-and-materials?

○ What is your projected timeline/Can you meet our timeline?

● Meeting with the consultant to get a sense of how you will work together

● Developing a contract and detailed scope-of-work that explicitly states the services and deliverables the consultant will provide, a tentative timeline, project costs/fees, and a definition of the roles and responsibilities of your organization as compared to the consultant’s

Other Organizations and Initiatives. There may be other organizations or initiatives already operating in your community whose efforts could complement your project. Such organizations may include:

● Public health agencies

● Membership organizations such as Independent Physician Organizations or Primary Care Associations

● Hospitals or large healthcare systems

● Payers (especially their sponsored quality improvement projects)

You may want to discuss the resource needs of your project with these other organizations to determine whether there is an opportunity for a partnership or other collaborative arrangement. For example, if you are developing a project to provide care coordination services to your community’s diabetic population, but the participating primary care practices do not have the resources to offer these services, you may be able to partner with a hospital in your community that has care coordinators with extra capacity on staff -- or, through the participants’ pooling of funds, engage the hospital to add that capacity more readily than a single provider could. The participants could then enhance their care coordination capacity through the use of this community-based care coordinator.

Alternatively, perhaps a payer is already providing an incentive to providers who report on certain quality measures, and the payer has established good relations with the EHR vendors who service your community. By developing a partnership with this payer, your organization may find it easier to engage the EHR vendors in providing support to your intervention.

Even in small communities, the healthcare environment is likely to be complex and rich with stakeholders and their broad array of projects. By building relationships with these stakeholders, you have an opportunity to build on their successes and ensure that your intervention is truly “community-based.”
Develop a Budget. The process of creating a budget will determine approximately how much the project will cost. Although the detailed aspects of developing a project scope are beyond the scope of this handbook, some items to budget for include:

- Personnel
- Consultants
- Training, seminars, and conferences for your staff and possibly the participants
- New equipment, especially for IT (hardware, software and licenses, networking, service providers)
- Travel or reimbursement for mileage, gas, and related expenses
- Facility rental and catering for events and meetings (e.g., for kick-off, planning, and governance)
- Office infrastructure and operations, including conference calling

Note that HIT vendors commonly structure their offerings into packages or “tiers,” and they will charge extra for many things that are not explicitly mentioned in their packages. For example, if you are able to anticipate any additional training needs or interfaces between multiple systems, be sure to discuss these items with the vendor in advance so you know precisely what is included.

While developing your budget, you may want to analyze your intervention design to identify periods of intensive resource demands: your personnel needs and other resource requirements may fluctuate over time. Accounting for these now will give you more flexibility later.

If you haven’t already secured funding, your budget (or some version of it) can be attached to grant applications and other requests to potential funders.

Information Technology Infrastructure. A robust information technology infrastructure will help your team members collaborate with each other and the participants. Working with a project team to conduct a community-based chronic disease intervention requires a large amount of intense collaboration, and having certain tools in place greatly reduces the effort in achieving collaboration.

It is best to assess and fulfill your needs before the project enters the implementation phase, as it will be burdensome to be building an IT infrastructure in the midst of trying to launch the project with the participants.

Elements of your IT infrastructure may include:

- The basics: a file server, computers (esp. laptops) for your team, printers, internal network, sheet-feeding scanner(s), productivity software suite (Microsoft Office, Apple iWork, Google Docs, etc.)

29 Some of these items may be free of cost.
● A project website, domain name, and email for your team

● Hardware and software to assist in collaboration, including:
  ○ Webcams and headsets
  ○ Collaborative software or web-based services for teams
    ■ Filesharing (e.g., Microsoft SharePoint, Basecamp, Dropbox, Box.net, Google Drive)
    ■ Project management (e.g., Microsoft Project, Basecamp)
    ■ Web-based seminar, online meetings, video conferencing (e.g., GoToMeeting, Webex, Skype, Google Talk or Google+ “Hangouts”)
    ■ Client Relationship Management/Contact Logs/Bulletin Boards (e.g., Microsoft SharePoint, Basecamp, Salesforce)

● Flash drives and/or portable external hard drives

● A privacy and security plan to achieve HIPAA compliance for all of the above. This may include the use of encryption software such as PGP or TrueCrypt.

Making an inventory of which of these items for your organization or project team already has will help you identify gaps in your IT infrastructure. You can explore solutions to fill those gaps, make vendor and product selections, and include selected items in your budget (see above).

Note: PCDC’s experience is that in addition to the basics, the following items from the list can be especially helpful in enabling collaboration:

● Webcams and a videoconferencing service

● A web-based file sharing service, especially one that is directly incorporated into the user’s operating system, such as Dropbox or Box.net

● A “contact log” for logging team members’ interactions with participants and other project stakeholders

30 For more information, see http://www.hhs.gov/ocr/privacy/hipaa/understanding/coveredentities/index.html
31 Note: If your budget allows for it, you may want to purchase webcams for your participants. PCDC has found that a small investment in webcams can dramatically improve the engagement of participants in project meetings, training sessions, and other activities -- far more effectively than traditional phone calls. This is especially true if your service delivery model requires you to support a large number of practices that you cannot visit in person as frequently as you might prefer. Also, when the project is complete, the participants may be able to re-purpose the webcams to use them for daily office operations, such as taking snapshots for patient registration purposes.
In short, your plan for developing an IT infrastructure for your project team should focus on two things: collaboration and ease-of-use. As the pressure of the implementation phase of a project absorbs your team members, they will most likely only use technology that they find to be efficient; in our experience, a policy stating that team members “must” use a certain technology is not effective unless the underlying technology is easy to use and helpful to them.

As you assess your staffing, budgetary, and IT needs, you can assemble your team and orient them to the project.

**Assembling and Orienting Your Team**

Through your initial assessment of your project’s staffing needs and your staff’s capabilities, you developed a list of staff members who *could* contribute to the project. Your next challenge is to assemble this assortment of people into a high-functioning project team.

As mentioned above, when selecting staff members to join your team, key things to consider are:

- Skills, experience, knowledge
- Availability and competing priorities
- Ability to effectively collaborate with other team members

Once you have identified the team members who meet your criteria and have worked within your organization to ensure their availability, you can introduce them to the project and form the team. As a first step, you can meet with each team member individually and briefly explain the project, answering any questions and concerns. This will help to reduce any anxiety and is a good, early opportunity to obtain their buy-in. (Remember that each new member of your project team member is about to experience a change in their daily work, one that will be prolonged, so it is important to consider and address the reactions the team members may have. This is discussed more fully in “Change Management,” below.) Topics to cover in this one-on-one meeting, which may last just 15-20 minutes, could include:

- Very brief outline of the project, its mission, and some high level goals
- Explanation of why you selected the staff member for the project
- Brief description of the team member’s role on the team
- Identification of the other team members and participating practices
- Timeline
- Identification of competing priorities the new team member may have
- Discussion of any concerns or questions, some of which are likely to involve training needs or perceived knowledge/resource gaps
- Immediate next steps, the most important of which is the first full team meeting
Having met with each team member individually, you can bring the full team together for a “kick-off” or orientation to the project. Depending on the scope of the project and the number of team members, this meeting will probably have about 90 minutes of content. Your goals for this meeting may include:

- Ensuring the team’s **full understanding of the project**, including:
  - the selected disease and rationale for that selection
  - the mission statement
  - the goals
  - the participants and rationale for their participation
  - any high-level measures that have been identified
  - rough project timeline with major milestones or phases identified

- Clearly expressing the team member’s **roles and responsibilities** (including the project’s communication chain or organizational structure)

- Explaining the **resources** available to the team, with an emphasis on available training or any new resources (such as technology that they haven’t used before)

- Achieving the team’s explicit **buy-in** to the project. In other words, team members should leave the meeting motivated to contribute to the success of the project, and feeling accountable to do so

- **Scheduling** a regular team meeting. (You may ask them to bring their calendars to the meeting.)

- Establishing “team principles” through a team charter or other **values-based agreement** (described below; may be more appropriate at a second meeting)

- Answering questions or concerns that the team may have (**Q&A**)

- Setting the **agenda for the next meeting**

- **Immediate next steps**, some of which you have identified before this meeting and some of which you will hear from the team. These may include:
  - Holding the next team meeting
  - Assigning the team members to serve as the “leads” for specific participants, and briefing the team members on the participants
  - Reviewing or developing the full project plan with the team
  - Planning the first interactions and activities with the participants
At this kick-off, your team members may identify the gaps in their current knowledge regarding project subject matter. Therefore, you may want to go into the meeting with an idea of what training resources you’re able to provide: written resources, on-site or off-site training, training/shadowing from other staff members, or access to resources external to your organization. It’s important to establish realistic expectations: if obtaining training in content areas from third-parties is not feasible, it is probably better to communicate this as soon as it is confirmed. This may trigger the team members to work together to find other solutions to their training needs, such as dividing the work by volunteering to compile online resources related to each relevant content area, and sharing those resources with the team.

Ideally, you’ll be able to incorporate training/knowledge development into your project plan, so that your team gets exposed to the content before the project has fully engaged the participants; otherwise, team members will be so busy with the project work, they may not have time to partake in training, which may eventually slow the progress of the entire project.

In general, a kick-off meeting such as this one will probably involve the delivery of a large amount of new information to the attendees, so if you prepare a written introduction (such as a concise PowerPoint presentation), it will help the team members stay focused and refer to key points. If the design of the project is clear in your mind, and you prepare for this meeting by clearly documenting the items above, your efforts to inform the team members while reducing their anxiety are more likely to succeed.

**Establishing Team Principles of Operation**

As one of its first activities, your team may find it valuable to establish a “values-based agreement” containing the principles by which it wants to operate. This can help bond the team together in the early stages of the project, and gives them a document to guide them throughout the duration of the project. Such an agreement can be a useful tool to “re-calibrate” the team when they encounter stress and the team becomes strained.

The agreement may include descriptions of principles that the team values, such as trust, transparency, accountability, respect, etc. The agreement may also address how the team expects to express or implement these principles, and how to handle transgressions of the principles. The agreement may also make explicit roles and responsibilities of team members. One type of a values-based agreement is a “team charter,” which may provide additional pragmatic information such as strategies for effectively conducting team meetings and managing project work.

Developing a team-based agreement often takes small- to mid-sized teams 90 to 120 minutes of collaboration; the effort can be split across two meetings. Although a project manager or other team member can facilitate the session in which the team develops the agreement, you may find it beneficial to include a respected staff member or other experienced stakeholder who is not a member of the team to facilitate the session.

To develop the values-based agreement, the facilitator should first establish a basis for the discussion: asking or explaining why the agreement is useful, acknowledging that this topic can be sensitive, and establishing an environment in which team members can speak candidly but respectfully to each other.
Next, the facilitator can ask the team members in broad terms what principles they feel the team should embrace, or what concepts they have found useful or beneficial in the past. Common responses include: trust, respect, responsibility/accountability, collaboration, support of each other, support from leadership, clearly defined roles and responsibilities, access to required resources, etc. Often, the facilitator will be noting these principles in a visible space, such as on a whiteboard.

Once the principles are established, the facilitator can discuss each one in more detail, asking questions like:

- Why is that principle important to you or to a team?
- What does it look like when a team successfully embraces that principle?
- What does it look when a team doesn’t successfully embrace that principle?
- How should team members handle it when another team member violates that principle?

The team may elect to discuss in more detail how these principles will apply to team operations such as:

- How meetings are conducted
  - E.g., “respect” means arriving on time, not answering cell phone calls in the meeting, not interrupting each other, not dismissing other’s ideas
- The role of leadership
  - E.g., “Collaboration” means honoring the team-based process and listening to ideas from other team members; “Accountability” for leaders means providing adequate resources, protecting time, etc.
- Balancing workload
  - Although some members of the team may be experts in the interventions’ subject matter, those experts cannot do all the work, therefore “supporting each other” means balancing the work across different team members

Once the team has reviewed the principles and agreed on what they look like in practice, the session can end, and afterwards, the facilitator or project manager can document them succinctly in a document, and circulate the document to the team for review. At the next meeting, the team can suggest any changes; once these are integrated, you may encourage each team member to sign the agreement to indicate their endorsement of it.

Preparing the Participants
Community-based chronic disease intervention projects offer many challenges because they tend to involve a large number of disparate organizations with differing priorities, resources, and patient populations. Therefore, well-structured recruiting and preparation processes are important to the long-term success of
Identifying and Recruiting the Participants

From the earliest stages of designing your intervention project, you may have had some idea of which organizations and practices you thought should participate. As described above in “Designing Your Intervention,” you may have already met with some of them to get their ideas. As your project gets closer to launching, you can formalize and finalize the list of participants.

To identify the organizations you would like to participate in your project, consider these questions:

- Who is the target population for your project, and which healthcare organizations in your community service that population (directly and indirectly)?
- Which medical professionals in your community have the most expertise in the chronic disease the project involves?
- Which professionals in your community have the most expertise in the type of interventions the project involves?
- Who are the other healthcare-oriented stakeholders in my community? What benefit might they bring to the project? (Public health agencies, membership organizations, payers, etc.)
- What prerequisites are there for participating in the project? (For example, will you require that every practice has implemented an EHR?)

As you list these organizations, consider each one and determine whether it may participate in the project directly (that is, it will be applying the planned interventions in their practice) or indirectly (that is, it will play a supporting role in the project, not directly enacting the planned interventions). Generally speaking, the direct participants are those that your organization will eventually be supporting in helping to achieve the goals of the project. For example, if your intervention is engage a “community-based care coordinator” who helps coordinate care for diabetic patients from many different practices, the direct participants are those who will work with the care coordinator; the indirect participants might include a professional organization who helped in the recruiting process to identify potential candidates.

Classifying participants as direct and indirect will help you better communicate your expectations to the participants, and will help you plan your resources, as you will know which participants will require the bulk of the support your organization will provide.
To identify additional participants, you may want to consult with the professional organizations in your community and other healthcare providers, so you have a full sense of who may be available to participate in the project.

As you did when building your own team, you may choose to develop an “asset map” to cross-reference the resources you need from your participants with the potential participants able to provide those resources.

Now that you have identified the potential participants, you can formally recruit them into the project. There are a few important items to use in your recruitment efforts:

- A brief written summary of the project that you can use as the basis for your discussion with the potential participants’ leaders
- A participation agreement that details precisely what is requested of the participants, what support your organization (and others) will provide to them, what costs are associated with participation, and the timeline for the project (with major milestones). This agreement may be legally binding.\(^{32}\)

At this stage in the recruiting effort, it will probably be most productive and efficient to meet directly with only the senior leaders at your potential participants (i.e., those with decision-making authority). Your goal is to obtain organizational commitment from its leadership; buy-in from the rest of the organization can come later.

In recruiting potential participants, you may find it helpful to engage respected people from other organizations in the effort, such as your board members, the leadership of other hospitals and practices, etc.

Your efforts to recruit the indirect participants may not require a binding participation agreement, but it may still be in everyone’s best interest to put in writing the mutual expectations related to that participant, so leadership there can understand what is expected of them, and for how long. (This may help you later in the project when the indirect participant’s staff is responsible for providing support, and you need to follow up with senior leadership to ensure that is happening.)

You can also take this opportunity to discuss with the participant the direct and indirect costs associated with the project, such as for purchasing equipment, allocating staff time to new initiatives, any foreseen productivity losses, etc. Although planning for these costs may not be something you are directly responsible for, it will help the leader better understand the potential impact on his/her organization.

Once you have recruited a sufficient number of practices and other organizations into your project, you can assess their readiness to implement the project.

\(^{32}\) Note: Use your judgment as to when to introduce the legal agreement to the potential participant. You may want to obtain a verbal commitment at the first meeting, and then follow-up with this written agreement.
Pre-assessing the Participants

Before you begin working with the participants on the project’s interventions, you will want to have an understanding of their capabilities relative to the project’s needs and goals. This phase is called “pre-assessment” because it occurs before the formal launch of the project for the participant and involves items that may be tangential to the specified goals or measures of the project. For example, if your project is to establish a community-wide registry of diabetic patients, it will help your planning efforts to “pre-assess” the participating practices’ status Information Technology capabilities, including whether they have an EHR, whether their EMR can interface to other systems, whether they have a reliable internet connection, whether their EMR offers a registry function, etc. (An additional “baseline” assessment that directly addresses the project’s measures will come later.33)

It will probably be useful to create a standard pre-assessment tool that you can share with the practices. This tool should be divided into sections corresponding to the components of the project, including (for example):

- Basic information such as:
  - contact information
  - number and type of providers, nurses, other staff
  - number of active patients
  - patients seen per day or year, etc.

- Billing and front desk operations, including payer mix

- Health Information Technology, including number of computers, network capability, etc.

- Clinical operations, including number of active patients with the chronic disease that is the focus of the project

Useful tools for creating assessments include word processing documents (organized using tables), spreadsheets, and online survey tools such as SurveyMonkey34 or the “Forms” function of Google Docs.35 All of these methods enable you to compile aggregate data on responses.

Based on your available resources, you may need to decide whether this assessment will be a “self-assessment” that the practice itself performs, or whether someone on your team can conduct the assessment with the practice. Generally speaking, self-assessments may offer less reliable data, but require

33 See “Achievement Measures” and “Measuring and Evaluating Success” elsewhere in this handbook for more information.

35 [http://www.google.com/google-d-s/forms/](http://www.google.com/google-d-s/forms/)
fewer resources from your team at this early phase of the project. Assessments that your team conducts may offer more reliable data, but will require greater a resource expenditure to conduct. Determining which method is most appropriate is left to your judgment, based on priorities and available resources.

When you complete the pre-assessments, you will be able to use the information to address any gaps the practices have relative to the prerequisites of the project. For example, through pre-assessment, you may find that a participating practice does not have an EHR, or uses it only for a small percentage of patients. You can then determine whether to address these gaps in the context of the project work, ask the practice to resolve them independently before you begin working with them, or (in the case of a serious gap) exclude the practice from the project.

With the pre-assessment complete or nearly so, you are prepared to extend your project beyond senior leadership and engage the participants more fully.

**Assemble and Orient the Participants**

If a goal of your community-based project is to encourage project participants to work together and learn from each other, you may want to bring the participants together for a *community-wide project “kick-off” event* so that staff members from the participating practices learn about the project, meet your team, and -- most importantly -- meet each other and discuss the project. Next, your team members can meet individually with each participating practice and formally launch the project at that site.

**Holding a Community-Wide Event**

If you decide to hold such a community-wide kick-off event, some items to consider in your planning are:

- Will all participants meet at the same event, or should you have multiple events based on region or some other criteria (such as use of the same EHR)?
- How can you enable the participants to collaborate with each other at this event?
- What are your goals for the event?
- Who from each participating organization should attend? The senior leaders who committed to the project are probably best-suited to identify attendees, but in keeping with team-based approach to the project, you should encourage the participants to send providers, clinical staff, and other frontline staff, not just managers.

You should design this event to ensure that everyone in the room leaves with a shared understand of the project, including:

- What the project is intended to accomplish
- The rationale for the project (why this disease, why this method, etc.)
- A clear explanation of each participant’s role in the project
- A timeline for the overall project and (if possible) the participant’s milestones
- A description of the project’s governance structure
- An explanation of how the project will enable and encourage the participants to work together for the duration of the project (including any future sessions like this one)
- Next steps, including the formation of a project team at the practices

Activities that enable attendees to form new relationships and collaborate amongst themselves at the session may include:

- Pre-planning of a clinical activity related to one of the project’s interventions, shaped by discussion with other participants
- A group discussion among peers (doctors with other doctors, nurses with other nurses, etc) about some aspect of the project, such as expected resources demands or a clinical intervention
- A facilitated strategic planning exercise in which the group suggests community goals consistent with the project
- The development of a project-wide charter or values-based agreement (using the basic methodology described above)

In the design of this event, care should be taken to include a mix of presentations and activities: presentations on the project and content areas can be interspersed with interactive, collaborative activities so that all participants feel engaged throughout. Although it may be tempting to fit all relevant content into a single session, you may have a better chance of obtaining buy-in and maintaining enthusiasm by limited the initial event to about two hours. Other information that the participants need to know may be better delivered in separate meetings between your team members and the practices’ individual project launch meetings.

**Launching the Project with Each Participant**

After the community-wide event (or instead of it), one or more members of your team can meet with each participating practice individually to formally the launch the project there. In advance of this meeting, advise the participant’s senior leadership of the need to select a team to implement the project. PCDC strongly recommends that such teams (known as “project teams” or “change teams”) be composed of these roles:

- **An executive sponsor** who is responsible for the project, but does not necessarily attend many change team meetings
- **A clinical champion** who helps to set the clinical vision for the project and advocates for the project to clinical staff
- **A project manager** who is responsible for facilitating various aspects of the project and who is the primary point of contact for your team
- **Front-line staff** who interact directly with patients (front desk, medical assistants, nurses, etc.)
● An **administrative person**, such as the office manager

● A **person with HIT expertise**, particularly with the EHR

Note that a single person may fill more than one of these roles, particularly in small organizations.

When the team is identified, the member of your team who will serve as the “lead” implementation specialist can meet with the team. The agenda for that meeting may include:

- Introductions, led by the executive sponsor of the project
- Summary of the project (esp. for those team members who did not attend the community-wide meeting)
- An explanation from your implementation specialist about his/her role
- A discussion of the roles of the team members (as described above)
- A discussion of the requirements of the project in general terms, including teamwork, personal commitment, protected time, weekly meetings, etc.
- The creation of a values-based agreement for the team, or at least a discussion of the principles of teamwork; this may include an acknowledgement of the way people experience change within an organization and how to manage that change\(^\text{36}\)
- Scheduling of a regular team meeting
- Discussion of next steps, which will probably include setting practice-specific goals and developing a project plan
- Q&A

Once each practice has launched the project, your implementation work with them can begin.

\(^{36}\) For more information, see CCMC’s “Change Cycle” at http://www.changecycle.com/changecycle.htm
Chapter 3

Establishing a Governance Structure

**Introduction**

In addition to assembling a project team that will support your participating practices directly, your project will also benefit from having a governance structure. The mission of the governance structure is not to execute the project: that role belongs to you and your project team. Instead, the role of the governance structure is to guide the project strategically, from inception through sustainability planning and completion. A common governance structure uses one or more committees for this purpose. The committees will meet to understand the project, participate in strategic planning, and make high-level decisions and “course corrections” as needed. Because you are implementing a community-based initiative and it will be to the project’s benefit for you to involve many stakeholders in your community, the committees should include people who are not directly employed by your organization.

The steps involved in establishing a governance structure include:

- Selecting a Governance Mode
- Assembling and Launching the Governance Committees
- Planning for Sustainability

**Selecting a Governance Model**

In selecting a Governance Model, you have a variety of options, including using:

- Your organization’s internal management structure (reporting to a CEO or Executive Director)
- Your organization’s board of directors or a subcommittee of that board
- A single committee that serves like a “board of directors” for the project and is composed mainly of people external to your organization
- A combination of committees, including a steering committee, all composed mainly of people external to your organization
Each of these has advantages and disadvantages:

<table>
<thead>
<tr>
<th>Method</th>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Your Internal Management</td>
<td>● Streamlined chain of command and communications</td>
<td>● No community representation</td>
</tr>
<tr>
<td></td>
<td>● No recruitment required</td>
<td>● May not have expertise in all major project content areas</td>
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<tr>
<td></td>
<td>● Familiar personalities involved</td>
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</tr>
<tr>
<td>Your Board</td>
<td>● Streamlined chain of command and communications</td>
<td>● Your organization may be seen as the sole owner of the project</td>
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<tr>
<td></td>
<td>● No recruitment required</td>
<td>● Doesn’t broaden involvement beyond your organization</td>
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<tr>
<td></td>
<td>● Some community representation</td>
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<tr>
<td></td>
<td>● Familiar personalities involved</td>
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</tr>
<tr>
<td>Single Committee</td>
<td>● Streamlined chain of command and communications</td>
<td>● One committee may not have expertise in all major project content areas</td>
</tr>
<tr>
<td></td>
<td>● Some community representation</td>
<td>● Committee members may be overwhelmed by volume of work</td>
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<td></td>
<td></td>
<td>● Unfamiliar personalities</td>
</tr>
<tr>
<td>Combination of Committees</td>
<td>● Broad representation from the community</td>
<td>● Complex chain of command and communications</td>
</tr>
<tr>
<td></td>
<td>● Greater likelihood of expertise in many content areas</td>
<td>● Unfamiliar personalities</td>
</tr>
<tr>
<td></td>
<td>● Distributed workload among committees</td>
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The first several options may be appropriate for small projects (those involving around six or fewer participating organizations, for example), but for larger, long-term projects, PCDC recommends using the “combination of committees” model, as it distributes the workload, is more likely to encourage widespread support for the project in your community, and gives you access to diverse areas of expertise and perspectives. Because this approach also requires the most planning, the rest of this chapter focuses on it exclusively. Once you have selected this governance model, the next step is to determine what committees you need.

**Building a Committee Structure**

The governance model you selected involves a **steering committee** and multiple “subject-matter subcommittees.” The subject-matter subcommittees will be responsible for evaluation and planning specific aspects of the project. For example, a project designed to improve care management for diabetic patients by providing them with in-home Health Information Technology could have a steering committee, a care management subcommittee, and an HIT subcommittee:

![Figure 3-1]

Thinking through the needs of your project, you may identify the need for additional committees. For example, here are some subject matter committees that you can consider:

- **Clinical Subcommittee** to study and refine the proposed clinical interventions and help develop strategies for implementing the interventions

- **Quality and Evaluation Subcommittee** to refine your measures and evaluate the impact of the project.

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[37] See the attached “Sample Governance Structure” for a visual representation of this concept.
• **Finance Subcommittee** to guide how the project’s funds are disbursed, and perhaps to develop models to help participants determine the project’s financial impact on their organizations; may also have a role in planning the sustainability of the project

• **Health Information Technology Subcommittee** to assess the project’s HIT needs and plan solutions.

For a small project, the members of your steering committee may also be the only members of subcommittees. But larger, more complex projects require more planning and work, so having a committee structure to support these efforts can provide a great benefit to your project. This will very likely mean staffing the subcommittees with some representatives from the steering committee and others from your community who do not directly serve on the steering committee.

**Planning and Launching the Steering Committee**

At the heart of your governance structure is the **steering committee**. The steering committee serves as the ultimate governing body of your project, working with you to set the overall strategy and vision for the project. Responsibilities of the steering committee can include:

- Strategic planning
- Managing and serving on project subcommittees
- Solving dilemmas that the subcommittees cannot solve
- Making decisions about items that involve significant changes in scope, cost, or impact
- Intervening personally with leaders at participating organizations to address project challenges
- Communicating with public health agencies, media, funders, and others about the project

**Community Representation**

A steering committee should have broad representation from your community of stakeholders, especially from the participating organizations themselves. To accomplish this, you may consider classifying the organizations by region and type, and include positions on the committee accordingly. (For example, one representative from each hospital, one representative for private primary care practices in each participating county, one specialist from each county, one representative from public health, etc. For a more detailed discussion, see the case study “Assembling a Steering Committee” below.)

Whether to offer voting positions to the stakeholders such as payers, home health agencies, and public health agencies is very much at your discretion: it may be more effective to have them serve as liaisons to their own organizations rather than as fully vested members of the committee. It depends on the level of participation you expect them to have in the project.

Your plan for the composition of your steering committee must also take into account the size of the committee. It is important to balance the principle of obtaining broad representation with the need to have a manageable size. A steering committee of 15-20 people is probably enough to offer wide expertise and perspective, and will not be too difficult to manage, in most cases. A much smaller committee would be
appropriate for a smaller project. Now that you have identified the representation on the committee, you can determine who you would like to be on it.

Membership
An important factor in determining the membership of the steering committee is the role that each member plays within his or her own organization. Should the membership consist of administrators or medical providers, or some combination of the two? Since your project involves specific interventions in chronic disease -- interventions that will be carried out, in part, by medical providers -- it will probably be most helpful to have strong representation from medical providers on the steering committee. In fact, you may determine that provider engagement in your project is so critical, the steering committee should be composed entirely of providers. This approach places a large portion of responsibility for the project directly in the providers’ hands, a strategy that will likely increase buy-in not only for those providers on the committee, but also for participating providers throughout your community. If you choose this model of a “provider steering committee,” you may find it useful to recruit administrators from hospitals or large private practices into an “administrators’ subcommittee” so that their perspective can be included in the project at a strategic level. (This is because the providers from those organizations may not have the insight into administrative operations that can help to inform your project.)

Once you’ve determined the mix of roles you feel are best for your steering committee, you can reach out to the organizations or people you have identified, explain the project and its governance structure (including the responsibilities and obligations of those who serve on the committee), and seek members for the steering committee. A good approach is to contact the executive leadership of the hospitals and large practices, and ask the leadership to identify a suitable representative.

Project Medical Director
Your project’s governance structure should include a Medical Director. The role of the Medical Director is to assist in designing clinical interventions, advocate for the project to participating providers, and guide the work of any clinical subcommittees (see below).

If you do not already have someone at your organization who will serve as medical director of the project, an appropriate time to identify a medical director for the project may be during the steering committee recruitment process. This person may be an excellent candidate to be the chairperson of the steering committee, as he or she will have detailed knowledge of the clinical aspects of the project.

Operations
Once recruiting is complete, you can facilitate the first meeting of the steering committee. Agenda items for this meeting may include:

- Introductions of all members
- Orientation to the project, the governance structure, and the committee’s role

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38 This may include an “ice-breaker,” a facilitated activity designed to encourage participants who don’t know each other well to feel more comfortable sharing ideas with each other.
● Establishing a mission (which should very closely reflect the mission statement of the project, as described in Chapter 1, “Defining Your Project”)

● Creating a values-based agreement, charter, or other statement of the group’s principles, which may include:
  ○ A statement of commitment to the project
  ○ Expectations and guidelines for attendance and participation

● Selecting a chairperson, or establishing a process for doing so

● Determining which subcommittees are necessary, and which members will serve on which subcommittees

● Logistical issues, such as:
  ○ Defining quorum
  ○ Determining meeting protocol, including rules of order
  ○ Identifying a “communicator,” the person who will take notes or minutes, and help the committee communicate with its members, the project team (staff), and subcommittees
  ○ Scheduling regular meetings
  ○ Remote participation in meetings (conference call, video-conference, etc.)

● Immediate next steps

At a follow-up meeting, you can facilitate the committee in establishing its goals and identifying specific tasks to meet those goals. The committee should also establish a mechanism for communicating with its subcommittees and, where appropriate, assigning tasks or issues for resolution to those subcommittees. In most cases, this would involve some kind of “liaison” structure in which someone from the steering committee serves as a member (and possibly chairperson of) an appropriate subcommittee, and is responsible for communication between the steering committee and the subcommittee.

The committee should select its chairperson. In the context of a community-based chronic disease intervention project, attributes of a good chairperson include:

● Communication and “diplomacy” skills, so the person can be effective “ambassador” for the project in the community

● Project organization and planning skills, including effective prioritization

39 In most cases, monthly meetings are probably sufficient.
• Ability to facilitate meetings effectively and keep discussions on track

• Time to dedicate to the project on a weekly or possibly daily basis (depending on needs and expectations)

• Respect from peers

With a clear method of operations, mission statement, goals, and regularly scheduled meetings, the steering committee (with some continued help from you or your staff) should be prepared to help guide the project at a strategic level.

**Establishing Subcommittees**

The process for establishing the subcommittees is similar to the process for launching the Steering Committee, but you now have the benefit of a steering committee to help with the process. Key questions to resolve during this process are:

• What subcommittees does the project require? (See above.)
  
  ○ Consider whether there will be enough on-going work for that subcommittee through the life of the project. If not, perhaps an “ad hoc” (temporary) task force would be more appropriate.

• What kinds of roles should be represented on each subcommittee?

• What organizations should be represented on each subcommittee?

• How can I recruit members to each subcommittee? Should steering committee members help?

• Should a steering committee member serve as the chairperson of each subcommittee, or should each subcommittee elect its own chairperson?

To help answer questions about the most suitable subcommittee structure and who the ideal members of those committees would be, you may want to perform an “asset mapping” exercise to map the needs of the project to the resources you have available in your community. (See Chapter 2, “Preparing for Change.”)

As you resolve these issues and recruit members based on their skills, knowledge, and experience, you can launch each subcommittee in a manner similar to the way you launched the steering committee, placing an emphasis on developing a specific list of goals for each subcommittee. The members of the subcommittee can probably add a great deal of value to your project, as long as they clearly understand what is expected of them and what they can do help the project. As tasks arise, the subcommittee may find it useful to set up a “task force” or ad hoc committee composed of just a few members to explore an issue or perform a task.  

40 This also applies to the Steering Committee, who may establish “ad hoc” task forces to explore or guide specific issues, rather than establishing a permanent subcommittee for this purpose.
In your planning efforts, you may identify one subcommittee that is particularly critical to the success of the project: the Clinical subcommittee. Compared to the other subcommittees, the members may meet more often, explore issues in greater depth, and work more closely with you and your team, and may even work directly with project participants, if needed. For this reason, you may choose to identify them not just as a deliberative “committee,” but as highly active and engaged “Clinical Team.”

**Establishing the Clinical Team**

The Clinical Team is responsible for guiding the clinical strategy of the project. While your steering committee will have some role in this (especially if the steering committee is wholly composed of providers), the clinical team will be responsible for an in-depth examination of the clinical interventions and developing plans to successfully implement them.

The Clinical Team should be composed of medical professionals, and include representation from the different types of healthcare organizations in your community (primary care, specialty care, hospitals, etc.). At least some members should have the skills, experience, or knowledge to design specific clinical interventions. Ideally, this means having some familiarity with these items:

- The chronic disease that is the focus of your project
- Researching and applying evidence-based guidelines to the practice of medicine
- Developing written policies and procedures for patient care
- Evaluating the clinical impact of an intervention (if a separate evaluation committee is not addressing this)

Specific tasks for the Clinical Team may include:

- Fully **understanding the evidence** supporting the interventions that you have selected for your project
- **Developing specifications and plans** for the implementation of the intervention at participating practices to ensure the interventions are applied in consistent manner. (This may include working directly with your project team.)
- **Explaining the rationale** behind the interventions to participating providers and other clinical staff
- Working with you and the steering committee to **adjust the design** of the interventions if the original project design is found to be flawed
- **Writing articles** for medical journals or other publications regarding the impact of intervention

Your project’s medical director and/or other clinical staff on your team should serve on the Clinical Team.
Planning for Sustainability

As you create and implement your project’s governance structure, you can keep in mind the long-term sustainability of that structure. Questions to consider include:

- If your community does not already have a provider membership organization or planning organization, could the steering committee fulfill that role, even after the project has officially ended?
- Could the steering committee plan and direct different projects during the course of this one, or after it ends?
- What kind of support would the steering committee need from your organization or others if it persisted after the project ends?
- What role, if any, should the governance structure have in planning the sustainability of the interventions at participating practices after the project ends? As providers and administrators in your community, the committee members will have valuable insight into what will be required to sustain these interventions after direct support from your team (and project funding) diminishes when the project ends.

Incorporating these questions into your planning at this early pre-implementation phase will help you prepare for long-term sustainability planning later (as discussed in Chapter 8, “Monitoring and Sustaining Improvement.”)

In the meantime, you and your project team can move to the next phase of your project, “Understanding Your Setting.”
Case Study: Assembling a Steering Committee
A project’s mission was to improve care and outcomes of diabetic patients through the use of in-home Health Information Technology. The community of project participants was spread across four counties and had these healthcare stakeholders.

- 6 hospitals
- 95 primary care providers
  - 50 employed by private practices
  - 45 employed by hospital-owned ambulatory clinics
- 7 specialty practices
- 1 home health agency (visiting nurses)
- 4 public health agencies
- 2 physician membership organizations
- 1 regional payer

To adequately represent these stakeholders on a steering committee, the project manager classified them by region and type, and assigned a position on the steering committee accordingly. She drafted a governance plan for the committee that included the following representation:41

- One representative from one hospital in each county (in-patient) [4 members]
- One owner of a private primary care practice in each county [4 members]
- One representative for each hospital with ambulatory clinics [4 members]
- One specialist from each county, which happened to include a representative of each relevant medical discipline [3 members]
- One representative from home health [1 member]

The project manager decided that the payer, public health agencies, and physician member organization did not need a voting position. Instead, she contacted each and identified a liaison to the project.

41 There is no universal “right” formulation for your steering committee. This is simply an example to illustrate general principles of obtaining broad representation.
This created a steering committee with 16 members, plus the project manager. One issue the project manager identified with her plan was that 8 of the 16 members were hospital representatives (inpatient and ambulatory). To mitigate this issue, she considered seeking out just one representative from each hospital who would be familiar with in-patient and out-patient operations. She also spoke with the owners of several private practice owners to see if they felt this composition was too greatly weighted with hospital representatives. The private providers responded that because the hospital clinics are responsible for so much of the ambulatory care in the community, as well as caring for the diabetic patients in the in-patient setting, this composition was appropriate. She kept composition of the committee as planned, and helped to facilitate the committee meetings and operations to ensure the voice of the private practices received equal attention.
Chapter 4

Understanding Your Setting

Having a complete picture of the patient’s health environment and the clinical/operational measures relevant to the disease is essential for the success of the intervention. Tackling a chronic disease’s impact on a community requires a detailed strategy that addresses the elements of this setting.

Patient’s Health Environment

The first significant piece of understanding your project’s environment is understanding your patients’ environment. Here are some basic to answer about the patient to obtain insight into the type of work necessary to have a successful intervention.

1. **How is the patient diagnosed?**
   - A detailed look into how the patients are diagnosed reveals some of the complexities behind patient population.
   - The severity of the disease at diagnosis will play a role in determining the depth of the intervention.
   - Challenges in diagnosis directly correlate to challenges identifying patient population; without a clear method for identifying the target population (e.g., specific diagnosis codes), your intervention will remain ambiguous.

   **Further Thoughts:** What complications could there be in developing an intervention for a disease that is precursor to another chronic disease?

2. **What types of clinicians see the patient?**
   - Create a detailed list of the various services and specialists that the patient may encounter.
   - Understand how the appointments with these specialists are generated (e.g., the referral process, self-referrals, etc.)
   - Map the results of these consultations to understand the value of each specialists and the information shared. Do consultant reports make their way back to the primary care provider?
   - Identify any additional roles from these services that may be beneficial to have as part of the team at the participating practice or within the governance structure of the project.
   - While answering this question, discuss the impact of the patient’s interaction with that clinician; it will help to determine the level of attention the clinician’s service and practice may need from the intervention.
Further Thoughts: A patient with a variety of comorbid conditions may see 3 or 4 specialists on a regular basis. This may complicate the approach to the intervention. Does the intervention need to engage all of these services or could the intervention focus on just some of these services?

3. What type of institutions within the healthcare network is the patient exposed to?
   - Map out what organizations and institutions manage the care of the patient
   - Consider how coordination of this patient through these various institutions occurs
   - In what type of situations is the patient seen by these facilities? (emergencies, transition of care referrals, at home visits, etc.)
   - Investigate the level of training at these facilities. What training components may be associated with your intervention?

Exercise: Patient Health Network Map

Objective: To better understand how the patient navigates the health care system in his or her community.

Creating the Map:
1. Have the patient as the center of the map
2. Is the patient assisted with a “care navigator” or care coordinator at one specialty or practice? (E.g., primary care physician). If so, draw a direct line from the patient to that specialty or practice.
3. Document and connect the various institutions that the patient comes in contact with. Be sure to connect those institutions to either the patient (if initiated by the patient) or the navigator/coordinator identified in step 2. It may also be beneficial to distinguish between the types of connections (i.e. emergent, annual, isolated, transition of care)
4. Within the box representing each organization, list the types of clinical services that the patient will encounter there

Locating the Intervention: Review the map, and determine which of these organizations your intervention will affect. Apply the clinical expertise on your team to understand where in the map the intervention will be (1) most feasible and (2) most effective. Mark these with a check box or other indicator.

(An example of the map is included in this handbook.)

By answering these types of questions and completing this exercise, you can achieve clarity about how the patient moves through the health care system, and you will have a better understanding of your setting.
Intervention Measures

Understanding your setting also involves understanding the measures that will help you track the success of your intervention. In health care settings, measures are often classified as “outcome measures” or “process measures.” **Outcome measures** track a patient’s health indicators, such as blood pressure, HbA1C level, cholesterol, etc. **Process measures** indicate whether a clinical or operational process was completed or not (e.g., number of patients with eye exams, number of patients receiving tobacco counseling, etc.) Both of these are valuable when determining impact of a chronic disease and the intervention intended to address the disease.

Your next step is to decide on what measures are valuable and identify any complexities behind these measures.

1. **What is a measure?** There are many outcome measures and process measures that indicate a disease’s impact on a patient or within a community. Other measures or to identify flaws within an operational process in the clinical environment. A measure usually includes a numerator and a relevant denominator. (For example, “number of patients with HbA1C over 9 ‘over’ number of patients with diabetes.”) In general, measures should be:
   - Relevant to the scope of the project
   - Reflect the impact of the intervention
   - Scientifically sound. That is, they should be specific to the condition your project is intended to affect, and they should be able to reflect changes consistently over time.
   - Useful. A measure should facilitate operational and clinical decision making.
   - Feasible. Data collection and management costs and times should be offset by the value of the information obtained.
   - Clinically relevant. Process measures should have adequate strength of evidence linking them to desired outcomes.

Remember that some measures may already be in place for other quality initiatives. If you can re-use a measure for your project, this may save a great deal of time and energy for all involved. Measures may also come directly from clinical guidelines and standards developed by medical and quality organizations such as the National Quality Forum, the American Medical Association, the American Diabetes Association, the National Commission for Quality Assurance, and others.

Clinical and operational expertise also gives room for the clinical team to develop measures of their own; one of the larger challenges with this idea is having peer-reviewed research to back up the value of this measure.

**Further Thoughts:** Were there any clinical measures that made it clear that this disease was an issue in your community? Could those measures help you track the success of your intervention?

2. **What baseline data exists?**
• For the measures that you will select, there should be a comparative set of baseline data that appears before the intervention takes place
• The baseline data measures should have the similar specifics and parameters as the measures you will select to mark the effectiveness of your intervention
• Discrepancies between the denominators/numerators of the baseline data measures and the denominators/numerators of measures selected could compromise an argument for the value of the intervention
• Without a significant amount of baseline data (large sample size) that is relevant to your community (similar patient population and location), the relevance of your intervention or data may be challenged.
• The availability of baseline data or the capability to collect baseline may result in changes to the measures you have selected
• Tap into existing measures from other entities (NYS Data, MD Data Core) and previous projects to help identify baseline data
• Remember, **simplicity is key** – difficulty with historical or baseline data can easily overpower the team’s efforts which is a sign that there will be difficulty in measuring the success of the intervention

3. Selecting your measures
• Combine your knowledge of the clinical measures specific to the disease and knowledge of the baseline or historical data available or obtainable; this exercise should highlight some key indicators that could lead to a measure for success.
• Be careful not to “overload” your project with measures; prioritize the most significant clinical or operational measures and select a few measures from that list.
• Consider the process for continuous collection of these measures: will the collection of the data be manual reporting from frontline staff or will it be generated automatically through an electronic information system?
• Fully specify the denominators and numerators of the measures; consider any data (patients) that should be excluded, specific timeframes for data points, and the possibility of having the same denominator across the selected measures (e.g., all patients seen in the last 90 days, all active diabetic patients, etc.)
• For each selected measure, write out a “statement of significance” that clearly connects the measure to the chronic disease and how an intervention could result in a positive impact on this measure.

| Example Statement of Significance: “The re-admission rate for diabetic patients with Coronary Artery Disease is far worse than the national average. Our intervention will seek to reduce the re-admission rate through post-discharge follow-up, and coordination with primary care practices.” |
Develop Your Approach
As you further develop your chronic disease intervention, you can think critically about the chronic disease and your measures of success. This will help you formulate the details of the intervention.

Addressing the Measures
One way to start thinking about what type of intervention would be appropriate is to look more into what drives your setting, specifically your measures. What kinds of interventions are shown to correlate to an improvement in that measure?

Next, you can determine:

- What roles are actively involved in the operation? (E.g., providers, medical assistants, nutritionists, etc.)
- What resources does the intervention depend on for efficiency?
- What barriers are there for the intervention being completed successfully?

This is illustrated below:

![Diagram showing the relationship between roles, resources, and barriers in chronic disease intervention.]

- **Roles**: Who are the key players for this specific intervention?
  - *E.g.*, Primary care practice initiates referral to nutritionist

- **Resources**: What resources would enhance the intervention?
  - *E.g.*, Nutritionists with educational resources

- **Barriers**: What barriers exist for this operation?
  - *E.g.*, Availability of nutritional food in school district

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**Figure 4-1**

**Indicator**
E.g., Pediatric Diabetic patients with BMI > 30

**Influential Intervention**
E.g., Increase exposure to child nutritionist and programs

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The above map can help you plan your interventions and determine how to implement them. Keep the following items in mind when thinking of these interventions:

- How can the people involved in each role be supported by your project team and their colleagues?
  - Is there technology available to support this role in the operation?
  - What additional skills/training needs could help maximize the effectiveness/efficiency of the people in each role?
  - Who else can support them?

- Are the required resources for the intervention available, and of high quality?
  - Are those who use or need this resource aware of its existence? (E.g., third-party care coordination services, chronic disease support groups, etc.)
  - Could evaluating, refining, and expanding available resources be helpful? Who could your team partner with to make that happen?
Refining and Implementing Your Interventions

Refining Your Interventions
Now that you have established a governance structure and fully understand the environment in which you are implementing the project, you can further refine your interventions. This can include examining in detail the measures you have selected and refining the implementation plan for the intervention.

Connecting Measures to Action
Since you’ve selected your measures (in “Understanding Your Measures”), you can study whether the interventions you have planned to affect those measures are appropriate and feasible, and determine what will be needed to take an action to have an impact. Consider these questions:

- What interventions (activities) are most likely to have an impact on the measures you’ve selected? What does published, peer-reviewed research show? What does your Clinical Team suggest?
- What roles within participating practices are required to implement the intervention? (E.g., provider, nurse, MA, front desk)
- What resources are required to implement the intervention? (E.g., training, new staff members, new equipment, etc.)
- What barriers are there to effectively implementing the intervention at the practice? (E.g., not enough protected time, excessive cost, lack of training, etc.)
  - Remember to consider the patient in your evaluation of the barriers. Are there complications or concerns that the patient may express? For example, if your intervention involves referring patients to a specialist in another county, some patients may have travel issues. How will you resolve them?

Figure 5-1 can help you visualize these items so you can be sure to address them with the participating practices.
To explore these in more detail, consider:

- **What support** do the people in the identified roles need to perform the intervention?
  - Is there technology available to support each person’s role in the intervention? (Such as an electronic referral system, a searchable registry of affected patients, etc.)
  - Do people in the roles require additional skills?
  - How can people with the same roles support each other in implementing the intervention?

- **Often, the performance of a measure depends on the availability and quality of resources** available to support the operation(s) that affect the measure:
  - Are those who require this resource aware of its existence and how to access it?
  - Can your team help to evaluate, refine, and expand currently available resources?
  - How can the practices connect the patient to available resources? How can you help the practices do so?

- **What other relevant challenges exist for the patient?**
  - Does the patient have enough access to care address the disease?
  - What complicates the plan of care (including the intervention) for the patient?
Describing the Interventions in Detail

The questions raised above in “Addressing the Measures” are intended to inspire you to identify challenges and needs you are likely to encounter related to the interventions. To ensure that you’ve addressed them, you can put details of your intervention in writing. Exercise 5-1, below, can help.

Exercise 5-1: Intervention Details

<table>
<thead>
<tr>
<th>Intervention Name:</th>
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<tbody>
<tr>
<td>Measures:</td>
</tr>
<tr>
<td>What:</td>
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<tr>
<td>How:</td>
</tr>
<tr>
<td>Who:</td>
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<tr>
<td>When:</td>
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<tr>
<td>Barriers</td>
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<td>Resources:</td>
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<tr>
<td>Support:</td>
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</tbody>
</table>

- **Intervention name**: Select a short name for this intervention (e.g., “Refer to Nutritionist,” “Offer Smoking Cessation Counseling,” etc.)
- **Measures**: Identify the measures this intervention activity is intended to affect (e.g., “Average HbA1C level,” “BMI,” etc.) Refer to your list of measures.
- **What**: Describe the intervention in more detail and its relationship to the measure. (E.g., “By offering nutrition and exercise counseling to patients, we hope to reduce the average BMI level”).
- **Who**: Identify the people and roles who will participate in this intervention on your team and at the practice. (E.g., “Implementation specialists: Provide contact info for nutritionists.” “Provider: check BMI; refer selected patients to nutritionist”; “Front desk staff: Schedule appointment with nutritionist.”)
- **When**: Identify the timeline over which this intervention will occur. When will it start and end? Consider competing priorities and external events, such as the start of the school year, the summer or winter tourist seasons, vacations, etc.)
- **Barriers, Resources, Support**: Described above.
Planning Support for the Project

Now that you have documented some details of how the intervention will address your measures, you are ready to identify and document the specific project tasks, and how your team will support the practices in achieving their goals. In other words, you will document how the work will get done. An important step in this process is determining who will do what. This activity lays the foundation for developing a successful plan for implementation. (See also Chapter 6, “Implementing the Interventions.”)

Table 5-1 below lists some categories of tasks that are common among many chronic disease interventions. The table can help you clarify the answers to these questions:

- What kinds of tasks are involved in your project?
- Who at your organization will be responsible for these types of tasks?
- Who at the participating practice (large or small) will be responsible for these types of tasks?
- What role, if any, will the vendor have in these types of tasks?

You can customize this table to fit your project and governance structure.

Table 5-1: Project Tasks and Roles

<table>
<thead>
<tr>
<th>Task [Project Team Member]</th>
<th>Participating Practice - Small</th>
<th>Participating Practice - Large</th>
<th>Vendor[^43]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Implementation Project Management [Implementation Lead &amp; Specialist]</td>
<td>Project Manager, Provider, Office Manager</td>
<td>Project Management Team</td>
<td>Project Manager, Coach, Support Manager, Trainer</td>
</tr>
<tr>
<td>Clinical Operations [Implementation Lead, Clinical Team]</td>
<td>Principal provider (owner)</td>
<td>Medical Director</td>
<td></td>
</tr>
<tr>
<td>Technological Infrastructure [HIT Coordinator]</td>
<td>IT Consultant</td>
<td>IT Department</td>
<td>Technical Support</td>
</tr>
<tr>
<td>Finance and Billing [Financial/Billing Specialist]</td>
<td>Office Manager</td>
<td>Billing Department</td>
<td>Billing Specialist</td>
</tr>
<tr>
<td>Quality Assurance [Evaluation Team]</td>
<td>Provider, Office Manager</td>
<td>Quality Improvement Department</td>
<td>Trainer/Report Writer</td>
</tr>
<tr>
<td>Privacy &amp; Security [Privacy and Security Consultant]</td>
<td>Provider, Office Manager, IT Consultant</td>
<td>Privacy Officer, Legal Counsel, IT Department</td>
<td>Trainer/Specialist</td>
</tr>
<tr>
<td>Quality Improvement [Quality Improvement Specialists]</td>
<td>Provider, Office Manager</td>
<td>Quality Improvement Department, Data Analyst Team</td>
<td>Report Writer</td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

[^42]: Derived from *Medical Informatics, An Executive Primer* by Ken Ong, MD MPH. Chicago: Healthcare Information and Management Systems Society (HIMSS); 2011.

[^43]: E.g., an EHR vendor, a billing consultant, etc.
Managing Your Project
As you fully define who will be responsible for what, both on your own team and at the practices, you can also consider how to manage the project at a higher level, so you will be prepared to keep it on track as it becomes increasingly complex during the implementation phase. Consider these aspects of project management:

1. Scope
   - Define and control what is within the scope of the intervention
   - Be flexible when you truly need to redefine the scope, but be mindful of any scope expansion that drains your resources (human and financial), lengthens your timeline, or is not consistent with the mission of the project
   - Examine other ongoing projects to identify opportunities to share resources (E.g., other quality improvement initiatives in your area that may have already developed good relationship with EMR vendors.)

2. Time
   - Coordination of schedules and identification of competing priorities is an important aspect in meeting deadlines on time
   - Consider the complexity of the participating organizations’ schedules. (E.g., imagine a situation in which your project plan call for a task to take two weeks, but the vendor stipulates three weeks, and the practice can only dedicate one week. Reconciling these may require difficult decisions and adjusting priorities or scope)
   - Be mindful of how much time the intervention may take away from the practice’s other duties, such as caring for patients

3. Cost
   - Unplanned costs can cause the failure of an intervention, as it may have to be abandoned partway through implementation
   - If you have the expertise available to you, develop a cost plan or financial projection for the project – not just for your organization, but for the participants as well
   - Remind the practices that their productivity (and consequently their revenue) may go down during the high-intensity phases of the project. (This is particularly true during major HIT implementations). It’s better to be upfront about this topic and plan for it than to let it be a surprise later.

4. Quality
   - Organize check-ins to ensure that the standards of the planned intervention are being met. (E.g., if the plan was to follow-up with diabetic patients after their visit, make sure to occasionally ask whether that’s actually happening)
   - Remember to include the quality assurance of any medical equipment or IT hardware that is used in the intervention. An inopportune equipment failure can derail the progress of the intervention, costing time, money, and momentum.
5. **Communications**
   - Consistently communicate the goals of the project as a whole to all participants, and remind them how the interventions address these goals, including updates on progress with specific measures can also serve to increase buy-in.
   - Discuss with your team and steering committee the best way to communicate progress to stakeholders

6. **Procurement**
   - Pay careful attention to your project budget and your methods for procuring goods and services
   - Neglect in this area can affect costs and the timeline of the intervention
   - Organization of all contracts with outside vendors is necessary to reduce risks. Clarity in these contracts is essential. It is worth investing extra time in the beginning to achieve clarity because ambiguity can cause major problems later in the project when there is disagreement
   - Leave flexibility in your budget to adapt to changing circumstances

**Implementing the Interventions**

Now that you have designed the intervention and prepared your organization to make it, it is time to plan the implementation and execute that plan.

**Creating a Plan**

Previously, you designed the intervention. Now, we encourage you to think about how you will implement the intervention with the participants. The development of the plan should answer questions concerning timeline, resource delivery, tasks and action items, and key milestones. Once you create the plan, you can test it using a pilot. Through the pilot, you will have a sense of what worked and what didn’t work, and will have some insight into the feasibility of the timeline you created.

You can use the mini-guide below to build the plan for the project and the pilot.

**Structuring the Plan**

A few questions to create a framework for piloting the project and then implementing a plan for this intervention include:

- What are we trying to accomplish with this project? (Discussed in previous chapters.)
- How will we know that this project has been successful? (Discussed in previous chapters.)
- What is the timeframe for this project?
- How will we adjust our approach to improve our chances of success as we proceed?

Components of a good plan include:

- **Timeline for implementation.** Use project planning calendars to identify and document:
  - Regular meeting times
  - Deadlines for individual tasks
- **Tasks and Action Items.** List necessary steps to be taken by the participants to execute the intervention. This list will serve as the basis of each participant’s workplan, and should include:
  - Tasks and subtasks required to achieve the goal
  - Roles and availability. Assign tasks to team members who have the required skills (or can obtain them) and are able to complete them within a specified time frame.
  - Decision points/contingency plans. Identify key moments during the implementation that the team should stop to check their progress, and if necessary, meet to revise the plan (i.e., “regroup”).
    - For example, on a project involving the development of a registry for diabetic patients, a decision point at a certain date could include, “If 40% of the lab results showing on our registry are not the most current lab results, the site will stop the implementation and the project manager will engage the vendors to resolve the issue.” These decision points help to keep the project on target and ensure that efforts are not wasted.
  - A “notes” section to track relevant pieces of information about that task

- **Resource Requirements and Service Delivery Model.** Review the resources that you identified in the chapter “Develop Your Approach” and how and when you will make these resources available to the participants, including:
  - Instructions, templates, and worksheets that will ease the work they have to do “from scratch”
  - Tracking tools to monitor the status of individual tasks
  - Assessments of infrastructure, including technology, equipment, space, furniture, supplies, etc.
  - Identification and scheduling of external support requirements, including required vendor training
  - Financial planning and resource assessment, including providing reimbursement for required tasks as data entry and tracking any “in kind” contributions your participants are making to the project
  - A list of competing priorities at your organization and each participant, so you know what items may interfere with your ability to complete the project on schedule (planned vacations, construction projects, moves, etc.)

- **Key Milestones.** Identify critical accomplishments, markers, measures, or milestones that denote completion of various stages of the plan.
  - Identify the deliverables that signify a task is complete. (For example, “Vendors install software on all front desk computers,” or “Practice writes protocol for use of registry”).
  - Identify and track progress towards quantifiable goals related to implementation (e.g., “80% of frontline staff passed a competency test for use of our diabetes registry”).
• **Risks and Consequences.** Document the risks the team foresees, and what consequences the intervention may have. Consider:
  - The time it takes to perform the tasks associated with the intervention, and its impact on current workflows
  - The costs associated with the intervention
  - Questions that staff or patients may have about the intervention
  - What will happen if the intervention fails

Specialized software for project planning (such as Microsoft Project) is available and useful for very large projects, but you may find that for small and mid-sized projects, a well-organized spreadsheet is equally effective for planning timeline and resources, particularly when creating a project plan for an individual participating practice. You can create a supplementary document to provide information about many of the items mentioned above, including risks, decision points, competing priorities, and additional required resources.

**Testing the Intervention Plan**

Rather than adopt a “big bang” approach of attempting to implement the entire project all at once, many project teams find it more manageable, and more productive, to **“pilot”** the intervention with one participating site or subset of sites, study the results, and iteratively apply lessons learned to the next “wave” of sites. PCDC recommends this approach.

Benefits to this approach include:

- Staging of costs, risks, and time
- Less strain on patients and staff
- Involvement of participants in testing and development encourages buy-in

You may choose to perform this pilot with a high-performing participant, as that will provide the best opportunity to have an early success and not be distracted by “side issues” associated with working with more challenging sites. The high-performing site is also more likely to offer a “proof of concept,” which is a primary benefit of using a pilot. Also, it’s more probable that a high-performing group will be able to better handle challenges that come along with change.
PDSA

One model for piloting change is commonly known as “PDSA” or “Plan-Do-Study-Act.” As the name suggests, there are four stages of this model:

- **Plan.** During this stage, you develop the plan for the intervention you intend to pilot. The plan should include measures of success and a timeline for each phase of the PDSA.
- **Do.** The execution of the pilot with a selected participant. This period should be time-limited. (For small scale changes, trying something for 2-3 weeks is usually sufficient.)
- **Study** (also called “Check”). You gather the “lessons learned” from the participants, check the status of your measures, and either “do over” with modifications, or “act” to expand your efforts to a larger scope.
- **Act.** The expansion of the intervention to a larger set of participants or another aspect of the intervention.

Two other key factors in a PDSA include:

- **Iteration.** The PDSA cycle is repeated, correcting for errors and challenges in the previous cycle until it is ready to become a permanent or universal process.
- **Measurability.** The idea of measuring results should be an integral part of the process. To correct for errors, you must be able to gauge your progress or degree of success. Measurability is a main focus in the “Plan” and “Study” phases of PDSA.

It’s worth noting that there are some aspects of a project that do not necessarily easily fit into a PDSA cycle: contracting vendors, installing IT infrastructure, training before go-live, and so on. However, even in these cases, when time constraints allow for it, adopting an pilot-and-iterate model is still likely to yield results and knowledge that is more actionable that jumping straight to the “Act” stage of implementation.

**Plan**

Studying the project plan you created earlier, you can extract key components to pilot as part of the PDSA. For example, consider an intervention involves three major components: (1) the creation of a disease registry, (2) the hiring and training of a care coordinator, and (3) the implementation of a risk stratification process to classify patients as high, medium, or low risk. To determine whether your plan for each of these is feasible, you can conduct a PDSA on the creation of the disease registry at a single site. The plan that you create for this PDSA, then, should apply just to this particular site and for this particular component, but it should cover the essential items described above: the tasks, the roles/resources, the projected timeline, the measures of success, and so on. Be sure to also document the desired results, so that you can trace anything that went wrong after the first cycle.

**Do**

It’s time to try out your plan.

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Step 1: **Launch.** Ensure that you have effectively communicated with everyone involve in the pilot, and establish a feedback loop (e.g., a daily huddle) to capture information on how the pilot is doing. Provide clear, written documentation will help ensure that participants understand their role in the pilot (and the fact that it’s a pilot, not a permanent change to their workflow).

Step 2: **Execute.** Conduct the activities as planned. The lead implementation specialist should work with staff very frequently to ensure they are executing the plan as envisioned.

Step 3: **Document results and challenges.** The lead should work with the staff throughout to ensure that newly identified risks and challenges are documented.

Step 4: **Break.** Once this phase is complete (as determined by the pre-established timeframe), make sure everyone involved is aware that the phase is complete and the team will now evaluate the results. (If the phase appears to have gone well, you may choose to continue the intervention -- with continued support; if not, it’s best to place the process on hold until the results of the “Study” phase are known and applied.)

**Study**

To understand whether the intervention worked as intended and to effectively spread the intervention to the rest of the community, the team must study the results of the pilot. The team can work through the following items to get an understanding of what changes will be required before trying again or taking the intervention to the next participant.

1. **Complete the analysis of the results**
   a. Did the pilot achieve the expected results?
   b. If so, why? If not, why not?
2. **Summarize lessons learned**
   a. What factors contributed to the success?
   b. What problems did the pilot uncover?
   c. What is the plan for addressing those problems?

If the team feels the intervention could be improved before it is put into action, then conduct another “Do” phase, applying lessons learned. If the plan was successful and the team feels they do not need to improve it immediately, then that team can implement the process (“Act”), take on the next component of the intervention, and you can begin the PDSA process for this component with another participant. Even in cases where the “do” phase is considered a success, it may be helpful to continue to apply the PDSA cycle to that activity and to consider the process of continual improvement.

**Act**

With “Plan-Do-Study” behind you, you can update your implementation plan and roll out the remaining aspects of the intervention to all participants, applying the PDSA model along the way. It is critical during this phase to maintain clear lines of communication and a mind-set of adaptability. Communication between

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45 [http://asq.org/learn-about-quality/continuous-improvement/overview/overview.html](http://asq.org/learn-about-quality/continuous-improvement/overview/overview.html)
yourself, your team, and the participating practices will be essential to success. Your ability to adapt your plan based on unforeseen challenges will also contribute to your success. Again, the PDSA model insulates you from many of the risks associated with the implementation phase: by trying small pieces out with a subset of participants, your probability of success should improve over time.

Models for Team-based Implementation

Depending on the size of your organization and resources available to it, you will be providing some level of support to your project’s participants. At the very least, it is expected that you will provide regular information to them. Therefore, a clear service delivery model and a communication plan are essential pieces of the project’s implementation phase. The implementation team, i.e., the staff and other resources (consultants, volunteers, etc.), that support the participants in successfully completing the task should have a clear idea of roles, responsibilities, and communication channels. The participating practices also should understand these, so they are calling on the right resources at the right time.

Below are two models for implementation team structure. You may also consider developing a hybrid of the two, or switching models if the one you’ve adopted is not meeting the project’s needs.

Model 1: One Implementation Specialist Supports Participating Practices. The “implementation specialist” is the person on your team who is taking the lead with the participating practice, i.e., the “frontline organization” making the intervention. In this model, each member of the team serves as an implementation specialist who supports one or more practices. This one-to-many relationship works best when every implementation team member is fully informed on virtually all aspects of the intervention, and can guide the participating practice through each phase of the project.

The implementation specialist has specific responsibilities related to communicating to and supporting the practice, including:

- Serve as the first point of contact for the practice
- Disperse information about the project to the practice
- Lead the execution of the plan for intervention at the practice (with the close collaboration of a corresponding lead managed by the practice)
- Relay requests for information to appropriate content experts on the implementation team

This model is illustrated below.
Model 2: Multiple Content Experts Rotate through Participating Practices. In this model, content experts provide support to practice for those aspects of the implantation in which they are most skilled. This model is ideal for complex interventions that require a high level of knowledge on each different content area. For example, for complex clinical intervention, an individual with a clinical background may be the best resource for the practice during that phase. During the next phase, a new Content Expert supports the practice.

In tandem with these Content Experts, “communication leads” serve to keep the frontline organizations informed of major project announcements, and facilitate communication between you and the practice.

The role of the Content Expert, then, is to provide in-depth support to the practice regarding a specific the content area. The role of the communication lead is to communicate with the Content Expert, you, and the practice to maintain robust communication and report implementation risks and concerns to you (the implementation team lead).

This model is illustrated below.
**Sharing Information**

Implementation team members and participating practices need access to resources and information that pertains to the implementation throughout the process lifecycle. Software tools that enable this kind of remote collaboration include:

- **Microsoft SharePoint** is a web application platform that provides tools well-suited for project management, including file sharing, message boards, and an integrated spreadsheet editor.

- **BaseCamp** is a website specifically designed to enable collaboration among project teams. It offers to-do lists, wiki-style web-based text documents, milestone management, file sharing, time tracking, and a messaging system.

- **Dropbox** is a Web-based file hosting service operated that uses networked storage to enable users to store and share files and folders with others across the Internet, and it keeps these files synchronized automatically.

- **Google Docs** is a free web-based office productivity suite that includes applications for word processing, spreadsheets, presentations, and drawing. Because of the ease with which Google Docs can be used for document sharing and collaboration, it is a useful tool for project teams.

**Note:** Websites and software are subject to HIPAA regulations on privacy and security of data. Be sure to consult these standards to ensure you are in compliance. Generally speaking, Protected Health Information should not be shared on servers that are not under your direct control and/or are not compliant with HIPAA standards.46

46 For more information, see [http://www.hhs.gov/ocr/privacy/hipaa/understanding/coveredentities/index.html](http://www.hhs.gov/ocr/privacy/hipaa/understanding/coveredentities/index.html)
Chapter 6

Measuring and Evaluating Success

As part of the process for “Understanding Your Setting,” you identified key measures that play an important role in defining how the chronic disease affects patients and the community. You also collected baseline (pre-intervention) data for those measures. Now that the intervention is in place, those same measures can be used to evaluate the success of the intervention on an ongoing basis. At the end of the project, you will again collect data, and then establish the interval at which you (or some other organization) will continue to collect data for evaluation.

This chapter discusses:

- Evaluating the intervention to prepare for sustaining and monitoring it over time
- Reporting progress to staff, participants, and other stakeholders

Evaluation by Quantifying Progress

The first step in the ongoing evaluation process is to obtain the relevant data, i.e., the measures you developed in “Intervention Measures.” Some items to consider when measuring this data include:

- **When to collect the data.** It is important to identify a precise time frame for collecting the data. You can select a point in time to begin collecting data based on how long you predict it will take the intervention to be apparent in the data. For example, if you are evaluating the impact of an intervention on diabetic patients HbA1C levels, you will want to make sure that enough time has passed to allow patients to have had their HbA1C’s tested again. In other words, if the patients’ tests are performed only every three months, a suitable interval for collecting data would be every three months (at the most frequent).

- **Sample size.** Through the use of a modern EHR, you may be able to collect the measures for all patients the intervention includes. If not, you will need to identify an appropriate “sample size” of patients, so that you collect data for only a subset of patients. The sample size should be large enough to statistically reflect the larger population. For guidance on determining an appropriate sample size for your intervention, consult a team member or other valued resource with a background in population-based health studies, or review resources provided by public health agencies (such as HRSA) or research organizations.47

- **Randomization of the sample.** In cases where you must use a sample rather than report on the entire population, be sure to randomize the pool of patients you are evaluating, so that the sample reflects a broad array of the type of patients involved in the intervention. You want to be sure that

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47For example: [http://bphc.hrsa.gov/policiesregulations/performancemeasures/patientsurvey/calculating.html](http://bphc.hrsa.gov/policiesregulations/performancemeasures/patientsurvey/calculating.html)
your method for identifying a sample does not unintentionally “bias” the sample by including only patients with a certain age, gender, area of residence, or other attribute.

• **Replication of baseline collection process.** To understand the impact of the intervention you must have information about the status of your measures prior to the intervention. Baseline measures provide this knowledge. To accurately compare the baseline data to this evaluation data, you should collect the evaluation data using a method that closely adheres to the way you collected baseline data. If you change the method for collecting the data without correcting the resulting data, the deviation will most likely undermine the integrity of your evaluation data. (For this reason, we strongly recommend developing a plan for collecting data early in your project, testing the collection of baseline data to ensure it is feasible, refining the process as needed, and only then, using the method to collect baseline data.)

• **Targeted Reporting.** When trying to understand the impact that your intervention is having on a population, it is important to fully understand the most relevant data. In the case of interventions, this means distinguishing between an entire population and those who have been targeted for the intervention. For example, a practice interested in adopting an intervention may gather baseline data showing elevated HbA1C levels in a diabetic population, design and implement an intervention affecting just some of those diabetic patients for several months, and then gather data on all diabetic patients again. When the practice reviews the data, it may not see a significant impact on its diabetic population’s A1C levels. This may be because the practice did not sufficiently target its reporting: it would be more helpful to separate those patients who received the intervention from those who did not, and compare the two groups “before” and “after” the intervention. (For a case study in targeted reporting, see “Targeted Reporting: A Clear Way to See an Intervention’s Impact” below.)

### Interpreting and Presenting the Data

#### Interpreting the Data

Obtaining data for your measures will produce a set of results that you should review with your team and possibly other stakeholders. Once you’ve collected your data, consider these questions:

• What story does your data tell?
• Is this data consistent with your expectations? If not, why not? (It could be that your hypothesis about the intervention was wrong, or there could be a problem with the way the data was collected – such as EHR misconfiguration.)

Refer to your achievement measures to assess your progress toward performance goals. You will probably see that you are making better progress toward some of your objectives than others. You can use this information to focus efforts for the next phase of your project on key areas where your performance is not as strong as you would like it to be. You can present this plan to your team and the practices, using the data in support of your plan.

A few things to keep in mind after your first round of measurement:
• **Improvement takes time.** Your first round of evaluation may not show much change. After a few more rounds of measurement, you will begin to see trends in your data that show progress, stagnation, or diminished performance. If you are not seeing change over several intervals, you may consider whether the impact of your selected intervention can be measured within the timeframe you’ve established, or perhaps your measure is not the appropriate one for this intervention or timeframe.

• **Data can motivate your team.** When you present the data to your team, you are including them in the evaluation process, helping to keep them focused on the goals of the project and the real impact on patient outcomes. This may keep your team motivated to work towards better results, and will enable them to better respond to questions from the participating practices.

• **Data collection can be a painstaking process.** By sharing the results with the team and the practices, you are, in a sense, giving them a reward for the hard work of collecting the data. The team can then work with the practice to discuss the data collection process: *What challenges did we have during data collection? Are we sure that we are not missing data? Did we have success with this intervention?* The practice may then refine its workflow for collecting the data to make it more efficient, as long as they don’t alter the statistically significant factors in that collection process.

**Presenting the Data**

Next, you can prepare to present your results beyond the team, such as your board, community stakeholders, funders, etc. Each presentation of your evaluation data should be tailored to meet the needs of the specific audience. When customizing the presentation of the results, take the time to realign the evaluation with specific objectives and target goals you have identified, especially those that are of the most interest to that particular audience. For example, if presenting to your clinical team, you may focus on a few key measures that have the most clinical significance. By contrast, if presenting to a grant funder, you may want to show the intervention’s impact on process measures that correlate directly to cost savings.

Below are some items to consider as you assemble your presentation:

• **Be concise and use simple language.** Statistics and data can be overwhelming to many audiences. Identify the key results and present the measures that best represent the project. Those who want more detailed and complex information about the results can ask for it, and you can provide them more detail separately. In many presentations, telling the story behind the numbers is at least as important as the numbers themselves.

• **Use calculations that are easy to follow.** The evaluation method and means for analyzing results should be easy to follow for both team members and external reviewers. Leave the complicated explanation of measures and calculations for separate sessions with the QI experts.

• **Be visual.** Take advantage of visual options for displaying results. This includes charts, graphs, timelines and various other kinds of illustrations.

• **Highlight the most essential data.** Focusing on key measures will help your audience understand the significance of the intervention. Including information about project implementation, such as the time frame and participating practices, may be important when explaining the progression of the intervention.
• **De-identify any data with patient information.** In order to comply with privacy rights, any protected health information (PHI) must be removed from the presentation of the measures.  
• **Be prepared to describe your data collection process.** If you fully understand the process used to collect the data, along with the successes and challenges you encountered through that process, you will be well prepared to answer any questions your audience may have about the integrity of the data.

### Feedback for the Participants

As mentioned above, you can also share the evaluation data with participants to demonstrate how the intervention has directly affected their organizations and their patients. Having a regular opportunity for sharing the data with the practices may help further engage the practice. You might consider developing “score cards,” “dashboard,” or other tools for providing quantitative information regarding the practice’s performance. Such a score card may include these elements, for example:

- The overall objectives and target goals for that measure, across the community
- Any relevant national or statewide benchmarks or standards for that measure
- The aggregate performance of all participants for the most important measures
- The practice’s results for those measures

Repeating your data evaluation regularly and sharing the results will help you track your project’s impact and can help to encourage your team, practices, and other stakeholders to make progress toward their goals.

### Case Study – Targeted Reporting: A Clear Way to See an Intervention’s Impact

The following case study demonstrates the concept of “targeted reporting” of the results of an intervention and illustrates the importance of carefully selecting the data to collect, analyzing the data thoroughly, and clearly presenting that data to stakeholders. The intervention in this case study involved providing “health coaching” to diabetic patients.

### Intervention: Health Coaching of Diabetic Patients

- A health planning organization studied clinical outcomes among its community’s diabetic patients and discovered the average HbA1C level among these patients was significantly higher than statewide averages.
- The organization designed a community-based chronic disease intervention to address this issue, and selected “health coaching” as their principle intervention.

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49 “Health coaching” is a care management activity that involves discussing the basics of a care plan and self-management with patients, such as the nature of their disease, prescribed medicine, healthy behaviors such as appropriate diet and exercise, goals, etc.
• The organization supported the participating practices in training staff to provide health coaching to diabetic patients.
• The practices implemented health coaching for a randomized group of diabetic patients.
• After six months of all participating practices providing health coaching to targeted patients, the organization’s clinical quality committee gathered the data and analyzed the results, so it could present to the organization’s board:

• The clinical quality committee reviewed this data and concluded that the patients who had received health coaching had improved HbA1C levels. However, they determined that the difference between “before” and “after” was not very significant.
• Then, the clinical informatics specialist working with the committee determined how to report HbA1C levels for only those patients who had experienced health coaching, and compare those levels to the diabetic patients who had not received health coaching. This analysis showed a distinct difference between the two groups:
They presented the information in this comparative format to the organization’s board members, who could clearly see the impact of the health coaching intervention. The board then encouraged the practice to expand the scope of the intervention to include all diabetic patients. Meaningful targeted reporting is based upon two key concepts of data entry and extraction:

- **Identifying patients who received the intervention.** To evaluate those patients who received the intervention, you must be able to unambiguously identify them. Consider the best way to mark the records of patients who have been included in the intervention. Ideally, participants could use a field in the EHR to flag those patients. In working with your participants, determine whether they must customize their EHR to capture this data, who will capture the data (provider, nurse, medical assistant), and what impact the collection of that data will have on their current workflow.

- **Timestamp for the intervention.** In addition to knowing that a patient received the intervention, it is probably useful to know when that intervention occurred (and how many times). A timestamp – which indicates the date and time that the intervention occurred or was documented – will assist you in reporting on your measures later, allowing you to isolate the interventions that occurred within a given timeframe.
Now that you have begun the implementation phase of your project, you will soon be able to determine whether it is having an impact on your measures or not. To do so, you will need to establish a plan for monitoring the results. Later, as the project approaches its formal end, you can establish a plan for sustainability, so that the successful interventions can become permanent.

Monitoring Results

Because of the community-based nature of your project, monitoring the results can be a complex process. In most cases, reporting on results will not be as simple as launching a computer program, running a report, and instantly seeing the latest data on all measures from all participants. Instead, each participant is likely to have its own system (i.e., set of technologies) for reporting the measures to you, particularly if the measures are themselves at all complex. For example, using a centralized database, it may be relatively straightforward to determine the number of hospital admissions of diabetic patients in the last three months, but it may be more difficult to determine, for example, the number of active diabetic patients between ages 18-65 whose HbA1C is over 8 and who have received foot exams in the last six months. (As discussed previously, this is one of the reasons that choosing clear, feasible measures is an important part of selecting measures.)

Additionally, because of the complexity of reporting across an entire community, you will most likely not have “real time” access to the latest data at your whim. Instead, you can establish a periodic reporting cycle so that your team and the participants understand when they need to report data. This will help your team prepare for supporting the practices in reporting, and will also help the participants prepare.

In developing a plan for monitoring results, there are several key questions to answer:

- What will be monitored?
- When (or how often) will it be monitored?
- Who will monitor it?
- How will it be monitored?

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50 Note that one of the key long-term goals of Health Information Exchange (HIE) is to enable this kind of reporting. Due to the technological complexities of summarizing diverse data into a standard format in a centralized location, however, this goal has not been fully realized yet. Nonetheless, the potential role of HIE is discussed elsewhere in this chapter.
At this stage of your project, the first question -- **what** will be monitored? -- is the easiest to answer. This is because you’ve already defined and refined your measures. (See “Defining Your Project,” “Understanding Your Setting,” and “Refining Your Interventions.”) Unless some unforeseen circumstance has arisen, you will want to include your established measures in your monitoring, at least for the first reporting period. (If the first reporting period demonstrates that one of the measures is simply not feasible to include in reporting, you can either adjust the process or eliminate that measure from the scope of your monitoring efforts.)

Determining **when** to monitor results largely depends on these factors:

- the scope and complexity of your project
- the number of measures, combined with the complexity and workload associated with reporting on each of them
- the time interval that your intervention requires to produce results

If you have a short-term project with only a few simple measures such as weight, blood pressure, and HbA1C levels, and each participant has built-in report to average the results across the targeted population within a specified date range, then you could use an interval of every month or two. However, you may not need to see monitor the data so closely, or perhaps you don’t have the staff to compile the data reported to you. An interval of every quarter is perhaps more appropriate.

For projects with many measures or measures for which the reporting process is not simple and fast, then a reporting cycle of every 4 or 6 months is more sensible. For longer-term (multi-year) projects with several complex measures, a 6-month interval may be the right balance of frequency and manageability for all involved.

**Note:** It is extremely important to keep in mind the burden that your project’s monitoring process places on your participants. PCDC has seen cases in which the burden of monitoring outweighs the benefits of participating in a community-based project for some participants, dramatically reducing buy-in from the stakeholders. We recommend that you strongly consider the impact of on your participants when you select measures and develop the plan for monitoring them.

Since you first established your measures, you probably had some sense of **who** should report each measure. For projects with a diverse set of participants, some measures will only apply to certain stakeholders. Planning who will report each measure will also help you avoid redundancies and conflicts in your data. For example, consider a diabetes-focused project that involves primary care providers, hospitals, and specialists (such as endocrinologists). You could ask all stakeholders to report the HgA1C levels of their diabetic patients quarterly. However, during the reporting period, a single patient may go to a primary care provider, the endocrinologist, and the hospital. All of these participants may have data on this specific measure. When the data is reported back to you, how will you know (1) how many patients are included in your sample, and (2) which HgA1C level is the “right” one for this particular patient? Think through the origins of the data and what will happen when you aggregate all of it when determine who should be reporting your each measure. This topic can be the subject of a lively conversation for your clinical team.
Present each measure, and some ideas for gathering the measures, and they will likely be able to solve some of the issues related to collecting the data, and may identify others.

Also, during this planning, you will want to identify precisely who at each practice will gather the data: in most cases, it will be a person who is expert in the use of the EHR, especially the reporting capability. If that person does not exist at the practice, another staff person may need training from your team or the vendor on how to run the appropriate reports. (This is discussed in more detail below.)

Finally, you can determine how the data for each measure will be gathered. Consider these important questions:

- What is the operational or technological process for inputting the source data? (E.g., documenting the appropriate data in the medical record.)
- What is the operational or technological process for gathering the data?
- What format will the data be reported in?
- What support will the participants require from your team to gather the data?

Before you can gather the data, you need to be sure that the participants have the capability to enter (input) the data in their medical record, and know how to do so. Documenting this process for them may help the “adoption rate” among providers or other clinical staff. If they have clear instructions on exactly what they need to do, they are more likely to enter the data.

Or, consider a more complex scenario. Perhaps during the planning stage, a stakeholder advised you that they could enter a value for the measure, but as the providers began the process of implementation, they realized they cannot capture the data as a “discrete” value that can be reported on automatically via their EHR. Instead, they have to enter the data in a comment field or similar. As a result, their EHR cannot automatically average this particular measure across their patient population. To address this issue, an HIT/EMR specialist on your team or in the practice could work with the EHR vendor to create a “custom field” where this data can be entered and used to populate a report.

To gather the data, there are a few models you are likely to encounter:

- **Fully automated.** A robust Health Information Exchange or other centralized database already captures the measures you need. You can work with the HIE or proprietors of the database to build custom reports to periodically gather the data. (This is an ideal circumstance, but uncommon.)

- **Individual EHRs with robust reporting.** If your stakeholders have modern EHRs with robust reporting capabilities, the process will likely involve a one-time effort to develop a set of custom reports that gather the data you require. To develop these custom reports, you can work the EHR vendor, someone with EHR reporting expertise at the practice, or a third-party consultant. (This effort can significantly expand your planned timelines for the project, so account for it in your...
Building Community-based Chronic Disease Interventions - A Handbook

- **EHR with limited reporting or no EHR.** If the practice has a dated/legacy EMR with limited ability for customization or customized reports, the burden on the practice to provide aggregate data to you will be greatly increased. In fact, it could very closely resemble a manual chart review, just as if the practice had no EHR at all. As noted above, when working with such practices, it is important to be mindful (and probably explicitly address) the effort the practice is putting into providing data to you. If you can support the practice through this process in some way, it may improve motivation at the practice and get you the data more efficiently.

The **format** of this data is important to your ability to efficiently aggregate and process it. Rather than ask each participant to, for example, send you their results in the body of email or call you on the phone and report them, it can save you a great deal of time and reduce the risk of errors if you provide a structured template for them. This template can be a word processing document or spreadsheet. A spreadsheet is perhaps the most efficient format, as you can more readily process the data statistically. *(Note: An example of such a template is in the attached “Measures Reporting Tool.”)*

Before you ask the participants to input or gather the data, it may be helpful to provide them with clear documentation of how to use their system to do so. If you have the resources on your team, you can develop a brief “how to” guide or “cheat sheet” with screenshots and instructions for each EHR in use on the project. Or, perhaps someone at the practice could work with you to develop such a guide. Providing such a guide will probably be far more effective in getting you good results than a request such as, “Please fill out this form and return it to us.” Even better, if you have the resources to provide direct support to the practice in gathering the data (e.g., through a remote session or in-person visit), you will reduce the burden on the practice, be more assured of accurate and timely results, and be in a position to improve your relationship with an important stakeholder.

**Note:** You can document your plan for several items discussed in this section using the attached tool, “Measures Reporting Plan.”

As you launch your monitoring plan with the participants, be sure to solicit their feedback on the process, so you can understand the challenges they encounter. Work with them to overcome these challenges, and incorporate your lessons learned into the next reporting cycle.

**Monitoring Your Project Implementation**

In addition to monitoring the clinical and process measures you have selected, you will also want to monitor the overall success and progress of your project. Throughout the implementation phase of the project, consider these questions:

- **Are we meeting our major project milestones** on time? On budget? If so, why? If not, why not?
● Is the **project team** engaged? Over-worked? Successful? Feeling supported?

● Is the **governance structure** engaged? Providing useful perspective? If not, why not?

● Are the **participating practices** engaged with the project? Do I know how they feel about the project? What concerns do they have? What successes have they had? Are they reporting their measures on time? Are they collaborating with each other?

● Do other **stakeholders** know about the project’s progress? (E.g., public health agencies, professional membership organizations, board members of participating hospital and health networks, payers, etc.)

By reviewing these questions (and others of your own) from time to time, you can help ensure you are tracking the “pulse” of your project and you can use the answers to these questions to address concerns and address your course as needed.

In a community-based intervention project, it is likely that you and your team will be doing the same thing many times at different practices: launching the project, setting goals, implementing the interventions, assisting with reporting, etc. What are you learning from those experiences? What improvements can you make from one practice to the next?

A “debrief” with each practice and/or your team after each major milestone is achieved can help you continually improve the quality of your implementation. A “debrief” is a session in which you and the stakeholders in that particular activity meet to discuss the activity and determine what implementation methods were successful or not, so you can apply lessons learned to future efforts. Some questions to ask during a debrief include:

● What about our approach to this effort was successful? What was not successful?

● What about our communication with each other and with the practice was effective, or not?

● How closely did our project plan match what actually happened?

● If you had to advise someone else who was about to do this themselves, what would you tell them?

● What would you do differently if you had to do it again?

● What was helpful about the support you received from the project team?

● What other resources would you need to be more successful?

● What value do you see in undertaking this effort that we just completed?

These questions are similar, but sometimes asking questions in a different way can yield different results. In a debrief, a “neutral”, collaborative approach to understanding what happened can help everyone involved feel some closure about the challenges or problems they encountered during that phase of the project, and feel ready to move on to the next phase. The facilitator of the debrief should take care to establish an
environment in which people can be honest and respectful, without resorting to blame or defensiveness. The goal is to achieve a common understanding of how to improve the process for the future.

During the implementation, refer often to your project plan and ensure that it is up-to-date. You may want to track “actual” start and end dates of tasks in addition to “planned” start and end dates. In practice, this level of tracking can be quite cumbersome, especially when the “start” and “end” dates are ambiguous. But if you can find a level of the plan where you can track this (e.g., major milestones), that kind of tracking may help you better understand your ability to estimate timeframes for future efforts. The same is true for the other elements of your project plan. You can continually check and adjust your plan to determine your accuracy in predicting the staff you projected as completing tasks, the resources you identified, and the tasks themselves. Again, that kind of analysis will help you improve the quality of the project going forward, and future projects you undertake in the future.

Finally, throughout the project, your “beacon” will be your list of goals. This document will help you, your team, and all stakeholders stay on track and keep you all from being distracted. Continually sharing the list of goals is a great way to maintain focus and buy-in. In fact, you may consider opening selected participant meetings with a “recap” of the goals, answering the question that many may be thinking about, but few will ask: “Why are we here today?”

With all of these methods to monitoring your project implementation, the goal is to avoid making assumptions about the project and the stakeholders’ reactions to it, so that you can better manage it.

Sustaining the Project and Governance Structure
As your project approaches its formal end date, you may want to develop a plan for sustaining the intervention after the project ends. The decision whether to sustain the intervention depends on several factors, including:

- Was the intervention successful? Did your measures show improvement over time?
- Do the participants have the capability and capacity to sustain the intervention without the support the project offers? (E.g., financial and technical assistance.)
- If not, can your organization or other community resource provide some level of support to the participants?
- Do the participants have the desire to sustain the intervention? The intervention could be effective, but if it is too burdensome for the practices, they may not want to continue it.

If you decide to sustain the project, then you will need to define what aspects of the project to sustain, and how to sustain them. In other words, you will be transforming your project into a program. These aspects include, for example:

- The interventions themselves
• The collaborative model established between the participants
• The monitoring/reporting process
• The project team
• The governance structure

Sustaining the interventions may be as simple as checking in with all the participants, and asking whether they have the ability to continue practicing the interventions and have the desire to do so. For example, if your diabetes project involved establishing "group visits" for diabetic patients at each practice, and over the course of the project, each practice successfully held several group visits, the participating practices may report that they and their patients find these visits valuable, they understand how to continue offering group visits, and will continue to do so without additional support. However, you may find instead that the practices report they still face challenges related to the intervention, possibly due to ongoing costs, lost productivity, or lack of understanding of how to conduct the intervention. In this case, you can talk to the practice to more fully understand their needs. Combining the information you gather from several practices regarding the challenges of continuing the intervention, you will have completed a “needs assessment” of the practices, and can use that assessment to inform decisions about how your organization or another community resource can continue to support the project.

Through your needs assessment and analysis of your organization's ability to support the project, you may determine that your organization cannot, by itself, meet the needs of your participants who wish to continue practicing the intervention. In this case, you can talk to other stakeholders in your community, share with them the success of the project and the participants interest in continuing it, and work together to identify what resources you can offer. These other stakeholders may include professional membership organizations, payers, a local planning organization, public health agencies, and so on. (In other words, you can contact many of the stakeholders you encountered when you were defining the project initially.) Many of these may already be represented in your governance structure, and your steering committee may be an ideal group to lead the sustainability planning efforts. And, of course, you can bring the participants themselves together to identify solutions to sustaining the interventions. A meeting of these stakeholders could include these agenda items:

• Report on project success
• Testimonial to the desirability of sustaining the interventions from the participants
• Identification of resources needed to sustain the project (e.g., financial, technological, extra staff or training, clinical)
• Plan to address each of these needs as a community
• Immediate next steps
Since the goal of this planning period is sustainability, you may want to focus the planning on finding solutions that do not require additional grant funding. Although grant funding can help to sustain changes in the short term, it is not an ideal long-term solution, as it makes the survival of the interventions dependent on factors outside of your community's control. Therefore, the emphasis can instead be on questions like, "How do we support each other?" The answer to this question may include a financial element in which members of the community agree to pay to receive support from your organization or another community resource. As a group, you can determine whether the practices would be willing to pay a membership or "subscription" fee to receive support on an ongoing basis. Perhaps the larger healthcare organizations in your community (such as the hospitals) would be willing to step forward with a larger proportion of any support costs to decrease the burden on smaller clinics or practices.

If you didn't already establish a collaborative model during your intervention, you may want to include such a component in your sustainability planning. Elements of a collaborative model include regularly scheduled meetings or events with the program participants so they can discuss successes and challenges related to the intervention, and help each other address problems. Such a group may also pool its resources to obtain additional support (such as a part-time care coordinator or an EHR trainer). Elements of a successful collaborative group include:

- Clear mission statement
- Specific goals
- Leadership
- Communication model to share information among the group
- Regularly scheduled meetings
- Resources and logistics (financial, meeting space, food, etc.)
- Engagement of other relevant stakeholders (such as EHR vendors)

The sustainability plan should also address any ongoing reporting that should occur. Will the participants continue to report on the measures? If so, to whom? It may be to your organization, or perhaps to a public health agency or payer that has agreed to take over the monitoring of the program. Regardless of who will be receiving the monitoring data on an ongoing basis, ensure that the monitor will be taking some action on the data, such as aggregating the data and reporting results back to the community, or using it to identify areas of need for potential future projects. Also, if the monitoring is ongoing, ensure that the participants clearly understand all the elements of the monitoring/reporting plan (see above).

Will your project team transform into a program team? In other words, will a team at your organization offer permanent support to the participants to sustain these interventions? The answer to this question depends on several issues, including:

- Do the team members have the time to do so, or will they be allocated to other projects?
● Is there a business model or revenue source that enables your organization to staff the team?

● Which elements of the program can your team continue to support, and which ones can they not?

Finally, you can consider what role, if any, your governance structure will play going forward. If, prior to your project, your community did not have anything resembling the governance structure, you may want to consider establishing the governance structure as a permanent group in your community. Their mission could include not just the sustainability of your project, but also the identification, definition, and governance of potential future projects. The end of the project is a good time to review the success of the governance structure, modify it to suit the community’s needs going forward, and (perhaps) redefine its mission to support the development of other community-based interventions over the long-term.

**Finishing the Project**

With the sustainability plan assembled, you can to prepare to formally complete your project. As the end date draws near, ensure you have these items in place:

● Clear agreement among your stakeholders on the sustainability plan

● The final round of data from your monitoring of the measures

● An understanding of which of your project goals are completed, and which are not

● An organizing library of project tools, resources, and other materials you have created or gathered during the project.

To celebrate the successes associated with your project, you may want to bring the participants and stakeholders together to acknowledge their hard work, discuss the sustainability plan, and share with them any plans for future projects. If this isn't feasible, you or your team members may be able to meet with each participant individually to do so.

PCDC recommends that you gather the team together for a final “debrief” session (as described above) to discuss what went well and what could be improved for next time. You can write a summary of this debrief session and share it within your organization to contribute to the success of future projects. Such a document can also inform any final reports you must prepare for any funders or other stakeholders.

With these lessons learned and fully documented, your project is complete. If all has gone well, your community has had a positive impact on a chronic disease, and you will all be well-prepared to take on your next community-based chronic disease intervention project.
AHRQ. The Agency for Healthcare Research and Quality. A federal agency that “supports research designed to improve the outcomes and quality of health care, reduce its costs, address patient safety and medical errors, and broaden access to effective services.”

Buy-in. The concept of personal commitment to the goals of a project, including being motivated and feeling accountable to help it succeed.

Care Coordination. In general, care coordination refers to activities related to assisting a patient receiving the care and services appropriate to that patient. Examples of care coordination include facilitating transitions of care, transferring relevant information to appropriate healthcare providers, and following up with the patient or provider to ensure care was delivered. Care coordination is a broad term and no universal definition yet exists.

Care Management. In general, care management refers to activities intended to enhance the care of a patient, particularly those with chronic disease. Many models of care management exist, and may include activities such as “huddling” with those providing care to the patient before a visit, establishing group visits for patients, establishing protocols and guidelines for the care of targeted patients, and making a formal effort to engage patients in self-management activities (such as tracking their own blood sugar or blood pressure). As with “care coordination,” the term is broad and encompasses many activities.

CCZ. Care Coordination Zone. A community of healthcare stakeholders and participants in coordinated effort to implement a project. In this handbook, CCZ is a synonym for “community.”

Charter. See Values-based Agreement.

Chronic Disease. In general terms, chronic diseases are defined as illnesses that last a long time, do not go away on their own, are rarely cured, and often result in disability later in life.

CMS. Centers for Medicare and Medicaid Services. The federal agency responsible for oversight of Medicare and Medicaid.

Coaching. A method of providing technical assistance to project participants. Coaching typically involves helping participants achieve goals, rather than simply telling them what to do, or doing it for them. Coaching helps to achieve buy-in, accountability, and sustainability among the participants.

Community. For purposes of this handbook, a community is defined as a collection of stakeholders in geographic region in which healthcare organizations and their constituents (patients) exist. It may include

https://info.ahrq.gov/app/answers/list
http://www.ncbi.nlm.nih.gov/books/NBK44012/
but is not necessarily limited to primary care practices, specialty providers, urgent care centers, hospitals, nursing homes, public health agencies, supporting organizations, payers and others whose work is related to that region. The region may be a town, city, county, or multiple counties.

**EHR.** Electronic Health Record. Nearly synonymous with EMR, but implies a system that can interface with other EHRs and/or other electronic systems.

**EMR.** Electronic Medical Record. Nearly synonymous with EHR, but implies a contained system that does not connect to others.

**Evidence-based Guidelines.** “A series of recommendations on clinical care, supported by the best available evidence in the clinical literature.” Also known as evidence-based clinical practice guidelines. A source for these guidelines is AHRQ’s National Guideline Clearinghouse.

**Goal.** For purposes of this handbook, a goal is a statement of what the project is intended to accomplish. It is not as broad as a mission statement, but is less general than a task or objective.

**HbA1C.** The percentage of glycated hemoglobin in the blood. HbA1C is commonly used as a measure in the diagnosis and care of diabetic patients. This handbook often uses it as an example measure.

**HIE.** Health Information Exchange. A digital hub of healthcare-related information that is often populated by healthcare organizations in the community, including providers and payers. HIEs are often built and managed by a RHIO.

**HIPAA.** Health Insurance Portability and Accountability Act. A federal law passed in 1996 that addresses many issues related to health insurance and health information. The law “require[s] the Department of Health and Human Services (HHS) to adopt national standards for electronic health care transactions and national identifiers for providers, health plans, and employers.”

**HIT.** Health Information Technology. Any information technology related to health care, including hardware and software.

**Intervention.** For purposes of this handbook, an intervention is defined as an activity that is intended to have some impact on outcomes for the targeted patient population or community. In other words, the purpose of the project is to implement one or more interventions for a targeted population.

**Measure.** The item that is being monitored to determine whether the intervention is successful or not. Measures may be related to clinical outcomes (e.g., average blood pressure, percentage of change in total cholesterol, etc.), or process (percentage of diabetic patients receiving a foot exam, percentage of patients
offered tobacco cessation counseling, etc.), or related to project management (whether certain project milestones have been achieved). Synonyms for “measure” include indicator, metric, signifier, and (achievement) marker.

**Mission Statement.** A broad statement of the intervention project’s purpose. The mission statement is the foundation for the project’s specific goals.

**Monitoring.** The process of gathering and analyzing data from the project to determine its impact. It is a form of ongoing evaluation.

**Objective.** In this handbook, an objective is an intermediate task performed to achieve a goal.

**PCMH.** Patient Centered Medical Home. As defined by the National Commission on Quality Assurance, a PCMH is “a health care setting that facilitates partnerships between individual patients, and their personal physicians, and when appropriate, the patient’s family. Care is facilitated by registries, information technology, health information exchange and other means to assure that patients get the indicated care when and where they need and want it in a culturally and linguistically appropriate manner.”

**Participant.** An organization participating in the project. This handbook discusses “direct” participants, who will implement the interventions with their patients, and “indirect” participants who are engaged with the project, but perform in a supporting role to the direct participants.

**Practice.** A non-hospital healthcare organization that provides direct medical care to patients. The term is used very broadly in this handbook, and could include primary care, urgent care, and specialty practices, in an office or clinic setting.

**Project.** For purposes of this handbook, a project is the initiative that an organization develops and implements to achieve certain goals. A project involves one or more interventions.

**Project Manager.** The person responsible for overall management of the Chronic Disease Intervention Project. In this handbook, this person is referred to as “you.”

**Project Team.** The team members at the organization managing the project; i.e., the project manager’s team. Responsible for providing implementation support to the participants.

**Provider.** A licensed medical professional who provides the care to a patient. Commonly, this includes medical doctors, osteopaths, nurse practitioners, certified nurse midwives, and physician’s assistants (depending on their role within their practice).

**Registry.** A list of patients with a particular condition or meeting certain criteria. Often, this list is electronic and generated by the practice’s EHR.

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**Risk Stratification.** The process of classifying patients according to risk. For example, a practice may risk stratify its diabetic population, identifying those with Hg1AC levels over 8 as “high risk,” and then direct an intervention at these patients intended to bring their HgA1C levels down to a healthier level.

**RHIO. Regional Health Information Organization.** In most cases, an organization established to provide HIT support to healthcare organizations within a region. A RHIO often implements and manages an HIE.

**Technical Assistance.** Support provided to participants to assist them in achieving the goals of the project. In the context of a chronic disease intervention project, this may entail helping participants understand the clinical aspects of the intervention, helping them establish new workflows to adopt the intervention methods, and setting up infrastructure (such as EHR) to better achieve the goals of the intervention. (Note that “technical assistance” is not necessarily equivalent to “technological assistance,” which involves only information technology.)

**Values-based agreement.** An agreement that team members develop to guide their work together. It may include descriptions of principles that the team values, such as trust, transparency, accountability, respect, etc. The agreement may also address how the team expects to express or implement these principles, and how to handle transgressions of the principles. The agreement may also make explicit roles and responsibilities of team members. One type of a values-based agreement is a “team charter,” which may provide additional pragmatic information such as strategies for effectively conducting team meetings and managing project work.
Tools and Appendices

- **Tool 1: Aligning Chronic Disease with Achievement Measures**
- **Tool 2: Team Selection Asset Mapping Grid**
- **Tool 3: Sample Governance Structure**
- **Tool 4: Measures Reporting Plan**
- **Tool 5: Measures Reporting Tool**
Tool 1: Aligning Chronic Disease with Achievement Measures
Chronic Disease: __________________________

Questionnaire

Quality of Life

1. Are pain assessments generally completed for patients with this diagnosis? □ Yes □ No
   a. If yes, what information is drawn from the pain assessment? _____________________
      __________________________________________________________________________

2. Do patients with this diagnosis generally have problems with physical functionality (i.e. mobility, self-care)? □ Yes □ No
   a. If yes, please describe. _____________________________________________________

3. Are behavioral health assessments generally completed for patients with this diagnosis?
□ Yes □ No
   a. If yes, are there any glaring trends around this disease and its impact on the behavioral health of the patient?
      __________________________________________________________________________

4. Are there any other additional disease specific symptoms that may have a large effect on quality of life?
□ Yes □ No
   a. If yes, please describe
      __________________________________________________________________________

Public Health Impact (Cost Analysis and Prevalence)

5. Are there any costly procedures associated with the disease? □ Yes □ No
   a. If yes, please describe
      __________________________________________________________________________
6. What information about the cost of this disease on the health care system is available?  

____________________________________________________________________________________
____________________________________________________________________________________
____________________________________________________________________________________

7. What information about re-hospitalization rates is available for this particular diagnosis?

____________________________________________________________________________________

8. How do morbidity and mortality rates for this disease compare to other chronic diseases?

____________________________________________________________________________________

Summary
What items from the questionnaire are significant?

____________________________________________________________________________________

What items from the questionnaire when addressed by an intervention would be valuable?

____________________________________________________________________________________

Creating an “Achievement Measure”
Develop statements that identify what your intervention address and how it success can be measured. (For example, “Diabetic patients in our region are suffering with depression at alarming rates; this intervention will improve behavioral health services offered to our diabetic patients.”)

1. ________________________________________________________________________________

2. ________________________________________________________________________________

3. ________________________________________________________________________________

____________________________________________________________________________________

61 See the Chronic Disease Calculator (http://www.cdc.gov/chronicdisease/resources/calculator/index.htm) and the Cost Effectiveness Analysis Registry (https://research.tufts-nemc.org/cear4/default.aspx)
**Tool 2: Team Selection Asset Mapping Grid**

**Instructions:** This tool is designed to help you select the best possible team for the project. First, identify prospective team members. Then, score each of these individuals on the relevant skills provided (Clinical, Administrative/Operational, IT and Computer). Use a scale of 1 to 5 to assess each one. A “5” indicates that the individual strongly exhibits the skill. Finally, in the last column, indicate which of the following characteristics the individual exhibits:

- **Innovator** – open to new ideas, creative, interested in improvement; 
- **Risk taker** – likes change, not afraid to try new things; 
- **Team player** – committed, supportive, respected, accountable; 
- **Communicator/Listener** – facilitator, can articulate ideas well, listens to others’ ideas; 
- **Problem solver** – analytical, good at making decisions, solutions oriented; 
- **Detail-oriented** – pays close attention to detail, helps avoid things falling through the cracks.

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<tr>
<th>Potential Team Members</th>
<th>Relevant Skills</th>
<th>Characteristics</th>
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<tbody>
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<td>Clinical</td>
<td>Administrative/Operational</td>
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<td></td>
<td>1 Name: e.g., John Doe</td>
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<tr>
<td></td>
<td>Title: Provider</td>
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Tool 3: Sample Governance Structure

Sample Governance Structure

- Steering Committee
- Project Manager
- Project Team
- Clinical Team
- HIT Subcommittee
- Finance Subcommittee
- Administrators' Subcommittee
- Quality and Evaluation Subcommittee
**Tool 4: Measures Reporting Plan**

<table>
<thead>
<tr>
<th>Name of Measure</th>
<th>Who Will Report</th>
<th>When to Report</th>
<th>Process for Reporting</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Example:</strong> Average HbA1C for Diabetic Patients, ages 18 - 65</td>
<td>All participating primary care practices</td>
<td>Quarterly (Jan 1, April 1, June 1, Sept 1)</td>
<td>1. In the EMR reporting model, run the custom report “HbA1C for Diabetics (18-65)”</td>
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<td>2. Record the result in the “Measures Reporting Tool” worksheet.</td>
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### Tool 5: Measures Reporting Tool

**Practice Name:**

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<th>Measure</th>
<th>Date Range</th>
<th>Value</th>
<th>Target Value</th>
<th>Variance %</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Example:</strong> Average HbA1C for Diabetic Patients, ages 18 - 65</td>
<td>1/1/2012 - 4/1/2012</td>
<td>7.1%</td>
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<td></td>
<td><em>We increased our self-management teaching last quarter, and now we are seeing improvement in this measure.</em></td>
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<thead>
<tr>
<th>Measure</th>
<th>Date Range</th>
<th>Value</th>
<th>Target Value</th>
<th>Variance</th>
<th>Notes</th>
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