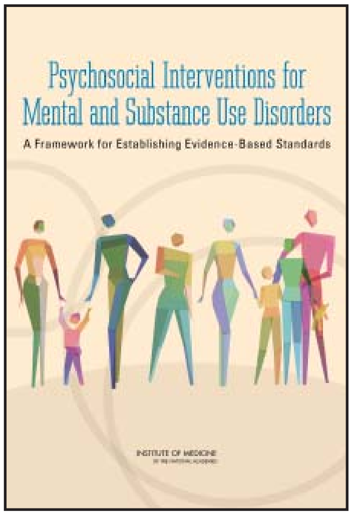
REPORT IN BRIEF

Institute of Medicine

JULY 2015

Psychosocial Interventions for Mental and Substance Use Disorders

A Framework for Establishing Evidence-Based Standards



Mental health and substance use disorders are a serious public health problem, affecting approximately 20 percent of Americans. The two often occur together and result in significant morbidity and mortality. The evidence base for the effectiveness of interventions to treat these disorders is sizable, yet no standard system is in place to ensure that people with mental health and substance use disorders receive effective psychosocial interventions.

Evidence-based psychosocial interventions often are not available as part of routine clinical care for mental health and substance use disorders. The gap between what is known and what is commonly practiced can be attributed to problems of access, training, insurance coverage, quality measurement, and fragmentation of care, including the separation of primary and specialty care and poor coordination of care.

Evidence-based psychosocial interventions often are not available as part of routine clinical care for mental health and substance use disorders.

The Patient Protection and Affordable Care Act (ACA), passed in 2010, and the Mental Health Parity and Addiction Equity Act, passed in 2008, aim to improve the delivery of and access to treatments for mental health and substance use disorders. In this context, the Institute of Medicine (IOM) convened an expert committee to identify key steps to ensure that evidence-based, high-quality care is provided to individuals receiving mental health and substance use services. The resulting report, *Psychosocial Interventions for Mental and Substance Use Disorders,* details the reasons for the gap between what is known to be effective and what is currently practiced, and it offers recommendations for how best to address this gap by proposing a framework that can be used to establish standards for psychosocial interventions.

PSYCHOSOCIAL INTERVENTIONS AND QUALITY OF CARE

Mental health disorders encompass a range of conditions, including anxiety, trauma, and depression, as well as eating, personality, and psychotic disorders. Substance use disorders encompass recurrent use of alcohol and legal or illegal drugs that cause significant impairment.

Psychosocial interventions may be applied on their own or in combination with medication in the treatment of these conditions. The IOM committee defines psychosocial interventions as *interpersonal or informational activities, techniques, or strategies* *that target biological, behavioral, cognitive, emotional, interpersonal, social, or environmental factors with the aim of improving health functioning and well-being.* Examples include psychotherapies, such as cognitive behavioral therapy, which aims to correct inaccurate or negative patterns of thinking; peer-support services; and community-based treatment.

The current quality of care for both physical and mental health and substance use disorders is less than ideal. One national study indicated that among patients with a wide array of physical and mental disorders, only about 55 percent had received recommended care, while another found that only about 32 percent of patients had received at least minimally adequate treatment.

THE PROPOSED FRAMEWORK

With the goal of improving the outcomes of psychosocial interventions for those with mental health and substance use disorders, the IOM committee developed a framework to help fully realize the consistent use of high-quality, evidence-based interventions in everyday care. Central to the framework is use of the consumer's perspective to inform the overall process. Evidence shows that consumers bring important personal experiences and knowledge of mental health and substance use disorders. The committee intends for this framework to be an iterative one, with the results of the process being fed back into the evidence base, and the cycle beginning anew.

The framework highlights the need to: (1) support research to strengthen the evidence base on the efficacy and effectiveness of psychosocial interventions; (2) identify the key elements that lead to improved health outcomes; (3) conduct systematic reviews to inform clinical guidelines that incorporate these key elements; (4) develop quality measures of the structures, process, and outcomes of interventions; and (5) establish methods for successfully implementing, sustaining, and improving psychosocial interventions in regular practice (see Figure).

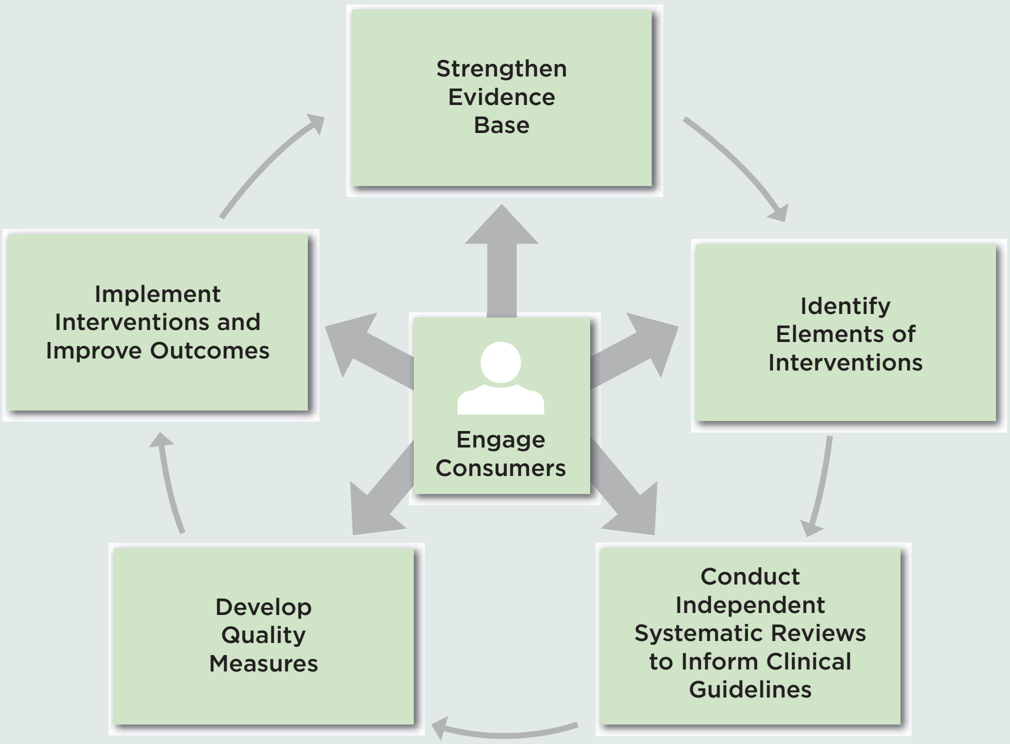


FIGURE IOM committee's framework for developing standards for psychosocial interventions.

With the goal of improving the outcomes of psychosocial interventions for those with mental health and substance use disorders, the IOM committee developed a framework to help fully realize the consistent use of high-quality, evidence-based interventions in everyday care.

THE IOM COMMITTEE'S RECOMMENDATIONS

The committee proposes a framework to guide efforts of the U.S. Department of Health and Human Services (HHS) to support policy, research, and implementation strategies that promote the use of evidence-based psychosocial interventions. HHS and other public and private funding agencies should ensure that consumers are active participants in the development of practice guidelines, quality measures, policies, and implementation strategies for participants in the development of interventions for people with mental health and substance use disorders.

The IOM committee recommends that public and private funders invest in research aimed at identifying and validating elements of psychosocial interventions, as well as expanding the evidence base for their effectiveness. A common terminology should be used for identifying and classifying elements across theoretical models and interventions.

Further research to expand the evidence base for psychosocial interventions, develop and test quality measures, and design and evaluate implementation strategies and policies should be built around the key elements that drive the effects of interventions. Additionally, HHS, in partnership with professional and consumer organizations, should support the development of a coordinated process for conducting systematic reviews of the evidence for psychosocial interventions and creating guidelines and implementation materials.

Steps must also be taken to assess the quality of care being provided to those with mental health and substance use disorders. Approaches used in other areas of health care can be applied to develop reliable, valid, and feasible measures of quality, but currently there is a lack of leadership in both developing and testing quality of care. HHS should designate an entity responsible for the development of quality measures to assess the structure, process, and outcomes related to mental health and substance use disorders.

A comprehensive quality framework should also consider the context in which interventions are delivered, including the characteristics of the consumer, qualifications of the provider, the clinic or setting in which care is delivered, the characteristics of the health system, and the regulatory and financial conditions that apply to the system. Purchasers, plans, and providers should design, evaluate, and adopt strategies that are aligned across multiple levels to continuously improve the quality of psychosocial interventions.

The recommendations offered in the report are intended to assist policy makers, health care organizations, and payers that are organizing and overseeing the provision of care for mental health and substance use disorders while navigating a new health care landscape. The recommendations also target providers, professional societies, funding agencies, consumers, and researchers, all of whom have a stake in ensuring that evidence-based, high-quality care is provided to individuals receiving mental health and substance use services.

CONCLUSION

The mental health care and substance use delivery system needs a framework for applying strategies to improve the evidence base for and overseeing the provision of quality evidence-based interventions in the delivery of care. A broad group of stakeholders must be involved to develop effective interventions that will help consumers. Through development of its proposed framework, and its recommendations within each component of that framework, the IOM committee offers a roadmap for implementing evidence-based psychosocial interventions and improving the outcomes for those with mental health and substance use disorders. ♦♦♦

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REPORT BRIEF APRIL 2015

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Vital Signs

Core Metrics for Health and Health Care Progress

Thousands of measures are in use today to assess health and health care in the United States. Although many of these measures provide useful information, their sheer number, as well as their lack of focus, consistency, and organization, limits their overall effectiveness in improving performance of the health system. To achieve better health at lower cost, all stakeholders—including health professionals, payers, policy makers, and members of the public—must be alert to which measures matter most. What are the core measures that will yield the clearest understanding and focus on better health and well-being for Americans?

With support from the Blue Shield of California Foundation, the California Healthcare Foundation, and the Robert Wood Johnson Foundation, the Institute of Medicine (IOM) convened a committee to identify core measures for health and health care. In *Vital Signs: Core Metrics for Health and Health Care Progress*, the committee uses a four-domain framework—healthy people, care quality, lower cost, and engaged people—to propose a streamlined set of 15 standardized measures, with recommendations for their application at every level and across sectors. Ultimately, the committee concludes that this streamlined set of measures could provide consistent benchmarks for health progress across the nation and improve system performance in the highest-priority areas.

A streamlined set of measures could provide consistent benchmarks for health progress across the nation and improve system performance in the highest-priority areas.

The Measurement Landscape

Health measurements are requested or required by many organizations for many purposes, including efforts to track population, community, and individual health; assessments of health care quality and patient experience; transparency monitoring; public reporting and benchmarking; system or professional performance requirements; and funder reporting. Many of these measures are very similar, with only slight variations in terminology and methodology. However, their differences are often significant enough to prevent direct comparisons across states, institutions, and individuals. In addition, many measures focus on narrow or technical aspects of health care processes, rather than on overall health system performance and health outcomes. According to the committee, the growing number of clinical measures, even those that provide valuable information, draws attention to narrow, specific elements and away from system capacity and effectiveness.

The necessity to collect, analyze, and store data for such a large number of measures also imposes a significant burden on providers, organizations, and the health care system as a whole. Preliminary research commissioned by the committee finds that the growth in measurement and reporting activities results in considerable expense and requires substantial time commitments—without a matching return on investment. The establishment of a core set of measures could improve efficiency and ensure a focus on the most important health outcomes.

The Core Measure Set

To select a core measure set, the committee first considers each candidate measure's importance for health, likelihood to contribute to progress, understandability, technical integrity, potential to have broader system impact, and utility at multiple levels. Next, in considering how the measures should operate as a set, the committee selects 15 measures that together have systemic reach, are outcomes-oriented, are meaningful at the personal level, are representative of concerns facing the U.S. health system, and have use at many levels. The core measures proposed by the committee are as follows:

1. Life expectancy: Life expectancy is a validated, readily available, and easily understandable measure for a critical health concept. Because life expectancy depends on a full range of individual and community influences on health—from cancer to homicide—it represents an inclusive, high-level measure for health.

2. Well-being: Well-being captures the subjective dimensions of health related to quality of life. Furthermore, levels of well-being often predict utilization of and satisfaction with health care. Self-reported well-being is a reliable indicator.

3. Overweight and obesity: More than two-thirds of Americans are overweight or obese, a fact that has causes and consequences that extend beyond the health system—including socioeconomic, cultural, political, and lifestyle factors.

BOX
Core Measure Set with Related Priority Measures

1. Life expectancy
Infant mortality
Maternal mortality
Violence and injury mortality

2. Well-being
Multiple chronic conditions
Depression

3. Overweight and obesity
Activity levels
Healthy eating patterns

4. Addictive behavior
Tobacco use
Drug dependence/illicit use
Alcohol dependence/misuse

5. Unintended pregnancy
Contraceptive use

6. Healthy communities
Childhood poverty rate
Childhood asthma
Air quality index
Drinking water quality index

7. Preventive services
Influenza immunization
Colorectal cancer screening
Breast cancer screening

8. Care access
Usual source of care
Delay of needed care

9. Patient safety
Wrong-site surgery
Pressure ulcers
Medication reconciliation

10. Evidence-based care
Cardiovascular risk reduction
Hypertension control
Diabetes control composite
Heart attack therapy protocol
Stroke therapy protocol
Unnecessary care composite

11. Care match with patient goals
Patient experience
Shared decision making
End-of-life/advanced care planning

12. Personal spending burden
Health care–related bankruptcies

13. Population spending burden
Total cost of care
Health care spending growth

14. Individual engagement
Involvement in health initiatives

15. Community engagement
Availability of healthy food
Walkability
Community health benefit agenda

The necessity to collect, analyze, and store data for such a large number of measures imposes a significant burden on providers, organizations, and the health care system as a whole.

4. Addictive behavior: Addiction, including to nicotine, alcohol, and other drugs, is prevalent in the United States, representing a complex challenge for the health system, communities, and families. Every year, substance abuse and addiction cost the country more than $500 billion.

5. Unintended pregnancy: Unintended pregnancy, a significant challenge for both individual and community health, is a measure that aggregates a variety of social, behavioral, cultural, and health factors—particularly women's knowledge about and access to tools for family planning.

6. Healthy communities: Individual health is a function of a wide range of socioeconomic and community factors, from infrastructure to social connections. Community health includes critical elements of health that fall outside the care system, such as housing, employment, and environmental factors.

7. Preventive services: Preventive services (for example, screening for hearing loss or counseling for tobacco cessation) present a valuable opportunity for both improving health and reducing costs.

8. Care access: A person's ability to access care when needed is a critical precondition for a high-quality health system. Factors that could hamper access to care include lack of health insurance, clinician shortages, lack of transportation, cultural and linguistic barriers, and physical limitations.

9. Patient safety: Avoiding harm is among the principal responsibilities of the health care system, yet adverse outcomes are common. Ensuring patient safety will require a culture that prioritizes and assesses safety through a reliable index of organizational results.

10. Evidence-based care: Ensuring that patients receive care supported by scientific evidence for appropriateness and effectiveness is a central challenge for the health care system. Currently, an estimated one-third of U.S. health care expenditures do not contribute to improving health. Aggregating carefully selected and standardized clinical measures can provide a reliable composite index of system performance.

11. Care match with patient goals: Systematically assessing each patient's individual goals and perspectives ensures that the health care system is focusing on the aspects of care that matter most to patients.

12. Personal spending burden: Care that is too expensive can limit access to care, lead people to avoid care, or prevent them from spending money in other areas of value to them—with far-reaching economic impacts.

13. Population spending burden: Health care spending consumes a large portion of the U.S. gross domestic product, dwarfing the health care spending of other nations. This burden can be measured at national, state, local, and institutional levels.

14. Individual engagement: Given the effects of personal choices on health, as well as the increasing use of personal health devices, it is critical for individuals to be aware of their options and responsibilities in caring for their own health and that of their families and communities.

15. Community engagement: Across the United States, communities have and utilize different levels of resources to support efforts to maintain and improve individual and family health—for example, addiction treatment programs, emergency medical facilities, and opportunities for social engagement.

The committee recognizes that these 15 measures will not be sufficient to meet every interest for each organization, nor are there established methods for measurement in each area. To begin to accommodate these challenges, the committee identifies 39 additional priority measures that can act as surrogates while refinement is under way (see Box).

Refinement of the measures and methodology will require leadership from stakeholders across sectors.

Implementation of the Core Measures

Successful implementation of the core measures will depend on their relevance, reliability, and utility to stakeholders. Implementation challenges include multiple competing priorities for stakeholders, the sizable degree of change proposed, and the slow pace of change overall in the health system. Progress can be accelerated by ensuring that the core measurement set is applied by, and adds value to, existing measurement activities. The committee stresses that leadership will be required at nearly every level of the health system. CEOs of health care organizations, payers and employers, standards organizations, and public health agencies will have important roles in the uptake, use, and maintenance of the core measures as practical tools. The committee recommends that the Secretary of the Department of Health and Human Services, with support from the Executive Office of the President, lead the effort to refine, standardize, and implement core measures throughout the nation.

Conclusion

The set of core measures proposed by the committee is a tool for enhancing the efficiency and effectiveness of measurement. Ultimately, widespread application of a limited set of standardized measures could not only reduce the burden of unnecessary measurement but also align the incentives and actions of multiple organizations at multiple levels. *Vital Signs* lays the groundwork for the adoption of core measures that, if systematically applied, could yield better health at lower cost for all Americans.

Committee on Core Metrics for Better Health at Lower Cost

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NATIONAL
QUALITY FORUM

Multistakeholder Input on a National Priority: Improving Population Health by Working with Communities—Action Guide 1.0

August 1, 2014

This first version of the report will be refined based on guidance from a range of groups implementing projects to improve population health. This report is funded by the Department of Health and Human Services under contract HHSM-500-2012-00009I task order 4.

Contents

Why Focus on Improving Population Health?

The United States has relatively poor overall health outcomes compared to many other developed nations, faces unsustainable healthcare costs, and continues to grapple with significant disparities in health status. Improving health within and across subpopulations is an important part of the solution. This Guide is meant for anyone interested in improving health within or among one or more groups of people. In other words, whether you are a leader within an organization or the community, public health professional, employer, healthcare provider, policymaker, consumer advocate, or any other person concerned about improving population health, this Guide is for you.

Yet, the health of the total population cannot be improved by one person or organization alone, or solely by public health agencies, or even by the vast healthcare sector. Many factors influence health and need to be addressed in a coordinated way by a range of individuals and organizations working together. This Guide can help you create a path forward to engage with others to increase the likelihood of success in improving population health.

Many people think of medical care when talking about how to improve health; however, medical care has a relatively small influence on overall health when compared with behaviors such as smoking and poor diet, physical environmental hazards such as polluted air and unsafe roadways, and social factors like low educational achievement and poverty.[1] Because the issues are wide ranging and the pressure to improve health and reduce healthcare costs is tremendous, population health improvement can seem too big a challenge for any one sector, organization, or individual to take on and have an impact. The only way to improve population health is to coordinate efforts.

Public health professionals have focused on population health improvement for many years at the tribal, local, state, and national levels. In the public health system, there are different levels of capacities and resources, skill sets, and coordination with partner organizations. The potential for accreditation is an important development to advance the effectiveness of public health agencies in fulfilling their mission. Of the 11 areas in which accredited public health agencies are held accountable, four go right to the heart of population health improvement: monitor health status and understand health issues; protect people from health problems and health hazards; give people information they need to make healthy choices; and engage the community to identify and solve health problems.[2]

Healthcare providers, health systems, and health plans have a particular responsibility to improve health outcomes. This requires taking an active role in promoting and improving healthy populations, rather than simply engaging with individuals when they are injured or sick. Making this shift is almost countercultural for some in the healthcare system, as American society tends to value personal independence and responsibility, and can be skeptical about coordinated efforts involving public and private organizations.[3] But the pressure to move in this direction is increasing. Fortunately, a number of contributors have a history and mission of responding to the broader needs of the community and vulnerable populations, in addition to serving individual patients or enrollees.

Beyond healthcare and public health, the concept of “health in all policies” suggests that even those who may not think of their work or actions as being about health — such as community advocates, housing organizations, employers, schools, universities, jails, military bases, transit systems, Native American tribes, land developers, and the like — make decisions and create environments that can help or hinder good health for the overall population or for a specific subpopulation. A few examples include:

- **Business leaders and purchasers in the public and private sectors** deal every day with the direct and indirect impact of poor health of their employees and family members. This appears as higher direct healthcare costs; for example, according to the Centers for Disease Control and Prevention (CDC), chronic disease such as heart disease, stroke, and diabetes accounts for 75 percent of the $2 trillion spent on medical care. In addition, the CDC estimates that the indirect cost of employee absenteeism, turnover, short-term disability, workers compensation and reduced work output may be several times higher than direct medical costs.[4] Beyond striving for a healthier workforce, many businesses also see value in supporting healthier communities, which could involve volunteering time and financial donations to activities such as housing projects, educational mentoring, and neighborhood safety initiatives.

- **Parents and other family members** are at the center of influence on the current and future health of children. Certain negative life events or Adverse Childhood Experiences (ACEs) can have a lasting impact on well-being, and include verbal abuse, living with a problem drinker, separation or divorce of a parent, mental illness in the household, and physical abuse.[5] For people younger than 18, these experiences cause toxic levels of stress or trauma, increasing the likelihood of poor physical and mental health, in addition to lower educational achievement, lower economic success, and impaired social success in adulthood.[6] When families and their larger social support systems succeed in avoiding or reducing the chances that kids are exposed to ACEs — or teach kids resiliency and other coping skills — this can positively affect the future health of our children.

- **Schools** are where children spend many hours of their day for much of the year. Not only is education an important influence on long-term health, but schools can serve as a hub for many more immediate health-promoting activities. For example, the Green Strides initiative of the U.S. Department of Education promotes sharing best practices and resources related to health and the environment, addressing issues such as air quality near schools and asthma.[7]

There is also a financial impact to consider. The cost of poor health is staggering, but there is evidence that certain efforts to improve health can save money. Some examples:

- Investing in “community building” — such as advocacy to support low-income or affordable housing, economic and workforce development, environmental improvements, and educational opportunities, among others — is an effective strategy for improving population health, and there can be a financial return on investment. For example, early quality child care and education have been found to have long-term positive effects, with every dollar invested saving taxpayers up to $13 in future costs.[8]

- Health-promoting policies can save money in multiple ways. For example, researchers estimated that prohibiting smoking in all U.S. subsidized housing could potentially save approximately $341 million in healthcare costs related to secondhand-smoke exposure, as well as millions more in avoided renovation expenses and fire damage due to smoking.[9]

- In Camden, NJ, leaders recognized that a small number of people who frequently used hospital services were generating about 90 percent of the hospital costs. One patient had come to the emergency department 113 times in a single year. Healthcare providers alone could not solve this problem. However, by taking a community-based team approach to addressing the social and personal needs of these patients — including housing, food, home visits, and social contact — they were able to stabilize the health of this subpopulation and head off medical issues that could cost millions of dollars to address. Their coordinated efforts resulted in a 40 percent reduction in emergency department visits and a 50 percent decrease in hospital costs.[10]

The chart below shows a clear example of how working on health improvement is much more effective than waiting until people get sick and need medical care. Within a population of 100,000 people ages 30-84, it is estimated that far more deaths would be prevented or postponed if everyone followed basic guidelines for good health when compared to the impact of consistently and appropriately using key heart-related medical interventions.[11]

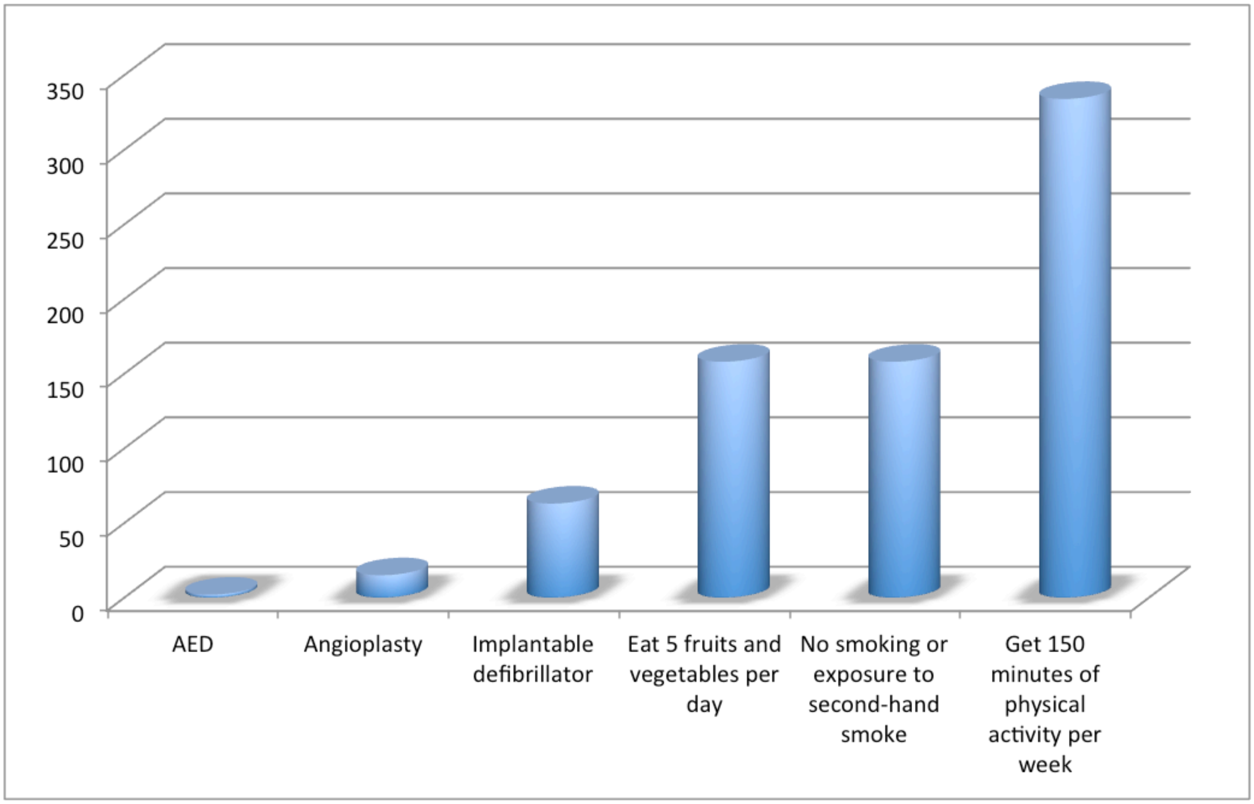

Figure 1. More Deaths Can be Postponed or Prevented by Meeting Good Health Guidelines, Compared to Consistently and Appropriately Using Heart-Related Medical Services[12]

A death prevented or postponed avoids the direct and indirect costs of illness and disease caused by poor health. Heart disease and death caused by smoking or obesity, for example, doesn't happen quickly: the years of poor health result in much higher medical costs, plus the cost of absenteeism and reduced productivity at work.

Above all, improving population health is about making life better for real people: our family members, co-workers, neighbors and ourselves. Preventing and postponing disease increases the odds that every person has the opportunity to live a long and healthy life.

Pieces of the "population health improvement" puzzle are being developed and, in some areas, coming together to create a more complete and effective effort. For example, establishing Accountable Care Organizations that align goals and perspectives across certain healthcare organizations is one approach, but not the same as a comprehensive effort to improve population health. Creating clear incentives is certainly an essential part of the big picture to improve population health. This is taking place in programs such as Medicare Shared Savings, the IRS community benefit rules for non-profit hospitals, public health accreditation, and the growing use of health impact statements as part of public policy decisionmaking. However, certain pieces of the overall puzzle to achieve better population health at the local, state, and national levels are still missing or hard to find.

Even with a shared commitment to improving population health, this is challenging work. No person or organization can improve population health alone, so coordinated collaboration is essential. However, different people and groups may be motivated by competing incentives and interests that are not aligned. Capturing and sharing information is often difficult, not only because the technology involved may not be available or interconnected, but also because of differences in definitions, cultures, viewpoints, regulations, and available resources.[13]

This Guide is intended to help light a path forward for any person in any organization to begin to address these issues. It's time for everyone to get more involved.

What is this Guide?

This Guide, tentatively called the *Guide for Community Action* (or *Guide*), is a handbook to be used by anyone who wants to improve health across a population, whether locally, in a broader region or state, or even nationally. It contains brief summaries of 10 useful elements important to consider during efforts to work with others to improve population health, along with actions to take and examples of practical resources.

There are many reports, websites, tools and other resources for every aspect of population health improvement. While each item may be very helpful, the sheer volume can be overwhelming. This Guide is intentionally short, with links to more information when details are needed. It takes a broad look at the issue, without duplicating the great work already done by others.

As an essential forum for driving improvements in health and healthcare, the National Quality Forum (NQF), with funding from the Department of Health and Human Services (HHS), has brought together a multistakeholder committee to develop this Guide through an open and iterative process. This "Population Health Framework Committee" (see Appendix E for the committee roster) includes population and community health experts, public health practitioners, healthcare providers, coordinators of home- and community-based services, consumer advocates, employers, and others who influence population health. The committee membership and transparent process mirrors the multidisciplinary, collaborative nature of effective population health improvement.

The Guide's purpose is to support individuals and groups working together at all levels — local, state and national — to successfully promote and improve population health over time. This is not about starting a program with a short-term goal that, when reached, one can declare success, shut down the project and go back to business as usual. This Guide encourages thinking of population health improvement work as a long-term initiative involving many types of organizations and groups across a region and at multiple levels, and as a team effort in which people take actions that, in some cases, fundamentally change how things are done. In other words, this Guide describes what it takes to make lasting improvements in population health.

The content in this Guide is based on evidence and expert guidance about what works to improve population health. This first version of the Guide — version 1.0 — includes questions, because more understanding is needed about certain topics. For example:

- The key elements listed in this Guide were chosen after researching the issues and gathering expert opinion. These 10 elements are ready for attention and comment, and practical testing by groups directly involved in population health improvement.

- The measures, data, tools, and other resources listed in this Guide were identified through an environmental scan[14] and suggestions from experts. With reactions and ideas from groups working to improve population health in the field, these lists will be refined to focus on the most useful, helpful items.

- Similarly, practical suggestions and input about the resources included in this Guide will inform stakeholders regarding ways in which these resources can be improved or expanded to be more useful for population health improvement.

The Guide will be updated based on the answers to questions and comments offered by people who read and use this first version of it.

How to Use the Guide

Like a handbook or "how-to" manual, the Guide suggests 10 useful steps toward building or refining initiatives to improve population health. The Guide offers ideas and links to resources for your consideration in building a coalition that can improve population health.

Standard Steps, Custom Approaches

Although the 10 elements presented in this guide are based on evidence and expert opinion, the best way to improve population health depends on the situation where the work is being done. Many different types of organizations and people, personal decisions, and social and environmental situations influence the health of individuals, subpopulations, and populations. The mix and degree of impact from these influential factors, or determinants of health, differ by location.

People focused on any type of population in an area — whether a small neighborhood or nationwide or anything in between — can use this Guide. How the insights from this Guide are applied for a given region will differ to fit the specific circumstances. A tribe in rural New Mexico may take one approach with its employer and community partners; a statewide coalition of many types of organizations in Georgia may take very different actions; and hospitals working with public agencies in Delaware, Maryland, and Virginia to improve population health in the tristate Delmarva peninsula may decide on a third course of action.

Start Where You Are

Whether refining ongoing efforts or starting a new venture, this Guide can help. In many regions, there are long-standing programs to improve population health, several of which are referenced in this Guide. This Guide can be used to assess and further refine or expand such work. In other regions, bringing organizations together to improve population health may be new, so this Guide offers a road map to move forward. Ideas for using this Guide include:

- **Prepare to get started**: Drive initial thinking about the current situation in your region and what likely needs to be done to succeed.
- **Bring others on board**: Share the insights you gain and encourage others to come to the table and participate in the initiative.
- **Take a deeper dive**: Use the description of each of the 10 elements for a general overview, then follow the hyperlinks under the examples and resources to dig deeper, explore options, and find what is most useful to your region.
- **Stay on course**: Post or distribute the handy checklist on page 13 as a quick reminder of the 10 elements that are important to success.

Important Words with Clear Definitions

It’s no surprise that there are differences in the words people use to describe this work, given the many types of organizations and individuals involved. Clear communication is critical to avoid misunderstanding and keep everyone focused on the shared goal.

Although many words associated with population health may come up in discussions, the terms listed below are among the most important for establishing a common understanding. These definitions are based on the work of experts and multistakeholder groups focused on population health, and are intended to reduce confusion due to different meanings for the same word, or different words used to mean the same thing.

1. **Population Health –** The health of a population, including the distribution of health outcomes and disparities in the population. [15]
2. **Population (also, Total Population) –** All individuals in a specified geopolitical area. [16]

3. **Subpopulation –** A group of individuals that is a smaller part of a population. Subpopulations can be defined by geographic proximity, age, race, ethnicity, occupations, schools, health conditions, disabilities, interests, or any number of other shared characteristics.[17]

4. **Health –** A state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity.[18]

5. **Determinants of Health –** Factors affecting the health of individuals in a population or subpopulation, such as the social and physical environment, behaviors, and healthcare. [19]

6. **Health Disparities –** Differences in health status or health outcomes within a population. [20]

7. **Health Equity** – The absence of systematic disparities in health or major social determinants of health between groups with different underlying social or economic advantages/ disadvantages.[21]

8. **Health Inequity –** Differences in health status between groups with varying social and economic advantage/ disadvantage (e.g., socioeconomic status, gender, age, physical disability, sexual orientation and gender identity, race and ethnicity) that are caused by inequitable, systemic differences in social conditions (i.e., policies and circumstances that contribute to health determinants).

These short definitions are intended to help everyone involved in the population health improvement work to "get on the same page" and avoid the pitfalls of miscommunication.

When thinking about these terms and discussing them with others, there are a number of important concepts to keep in mind. For example, the definition of population used in this Guide includes everyone in a geopolitical area in order to promote focus on improving the health of all individuals in a region, regardless of other characteristics. Geopolitical areas or regions can be determined by zip code, precinct, ward, county, district, metropolitan statistical area, state, multistate region, nation, continent, or worldwide. In contrast, a geographic area might be less precise — such as along the coast, or west of the mountains — and therefore may prove difficult in unexpected ways. Using boundaries that coincide with geopolitical designations may increase chances of finding useful data sources, as most publications that assess population health use population-based surveys that pull information across a region that has political and geographic significance.[22] Program funding and government regulation are often based on or defined within a geopolitical boundary, as well.

Subpopulations can be any type of group with shared characteristics, such as race, ethnicity, age employment, educational status, medical condition, or disability, and so on. This can also include groups that might be relatively rare — such as people with "orphan conditions," or transgender people — or some other defined group across long distances, especially because of the way technology and social networks enable people with shared characteristics to connect.

Using the definition of subpopulation is important for identifying inequities in health status (and related disparities in medical care, social services, and supports, etc.) among certain groups. The needs of the relevant subpopulations should drive the goals and objectives for health improvement activities implemented by clinical care systems, government public health agencies, and multisector partnerships and collaborations.[23] This promotes a “system within systems” approach where each of these sectors or organizations can work with a specific subpopulation (e.g., covered members, hospital referral area, or an at-risk group) in the context of a total population within a geopolitical area. This approach also accommodates the separate funding, implementation expectations, and data collection systems (often stand-alone) of the various sectors.[24] Here is the bottom line: one of the important steps for improving the overall health of the population is to address the health inequities of the subpopulations in greatest need.

The term “community” is often used interchangeably with “population” or “subpopulation”; however, that can lead to misunderstandings because there are many possible meanings of “community.” The boundaries of what defines a community are evolving, particularly in the era of the Internet and social media. To avoid confusion, this Guide generally refers to populations or subpopulations rather than communities and does not define “community health” as a separate concept. However, an important aspect of community is the power of relationships and the interconnectedness of people, organizations, and systems within a community. Such “system” thinking and focus on relationships are very important to population health improvement work.

The definition of health used here encompasses a complete state of wellness. The World Health Organization established this broader definition and has used it consistently since 1948. Understanding population health also requires noting the variation in health within subpopulations of people in the total population. It includes looking at patterns of health determinants, and the policies and interventions that link health determinants with health outcomes, both within and across populations.

Health is shaped by many factors, including individual biology, behaviors, and the physical and social environments where we live. Relationships with friends and family can have a considerable impact on health. These determinants combine to affect the health of individuals, subpopulations, and the total population. While access and use of healthcare services is often considered when thinking about health improvement, healthcare has less of an impact on population health when compared to other factors like the social, economic, and physical environment, and a person’s individual behaviors.

Disparities in health usually refer to differences in health status or health outcomes when comparing groups within a subpopulation or the population overall. Health equity, simply put, is the absence of these differences in health status or outcomes among diverse groups of individuals. Groups that are most often considered when addressing disparities are defined by race or ethnicity, such as Blacks/ African Americans, Hispanics/ Latinos, Asians and Pacific Islanders, and Native Americans/ Alaska Natives, in addition to persons with Limited English Proficiency (LEP). This is an important first step; however, disparities should be assessed for all vulnerable groups—including people who are disabled, pregnant women, children, the elderly, and lesbian/ gay/ bisexual/ transgender (LGBT) individuals.[25]

Quick View: Action Guide Key Elements

Ten elements important in successful approaches to improving population health are below. Check off items in this list as you go through them when starting a new project, or when refining existing programs.

✓	**Element**	**Questions to Consider**
	A self-assessment about readiness to engage in this work	*What types of assessments have already been done in efforts to improve the health of this population?*
	Leadership across the region and within organizations	*Which individuals or organizations in the region are recognized or potential leaders in population health improvement?*
	An organizational planning and priority-setting process	*Which organizations in the region engage in collaborative planning and priority setting to guide activities to improve health in the region?*
	A community health needs assessment and asset mapping process	*Which organizations in the region already conduct community health needs assessments or asset mapping regarding population health?*
	An agreed-upon, prioritized set of health improvement activities	*What are the focus areas of existing population health improvement projects or programs, if any?*
	Selection and use of measures and performance targets	*Which measures, metrics, or indicators are already being used to assess population health in the region, if any?*
	Audience-specific strategic communication	*What is the level of skill or capability to engage in effective communication with each of the key audiences in the region?*
	Joint reporting on progress toward achieving intended results	*Which organizations in the region publicly or privately report on progress in improving population health?*
	Indications of scalability	*For current or new population health work in the region, what is the potential for expansion into additional groups or other regions?*
	A plan for sustainability	*What new policy directions, structural changes, or specific resources in the region may be useful for sustaining population health improvement efforts over time?*

See the full *Action Guide v1.0.*for more details about each element, examples, and links to useful resources.

Ten Key Elements: Overview

A variety of factors are important for creating and sustaining successful approaches to improving population health. The 10 elements in this Guide were identified based on research and assessments of existing initiatives to improve population health. Many promising programs already include some or most of these elements. To improve the likelihood of long-term success, all 10 of the elements should be addressed when starting a new project or when refining or coordinating programs already in place.

Each section below describes what the element is, why it is important, and gives examples of how it can be done, and provides links to useful resources. Although the elements are numbered, the order in which they are addressed may differ, especially after completing the self-assessment.

Element 1: Self-Assessment of Readiness to Engage in this Work

What it is

Whether you are just getting started or working to refine existing population health improvement efforts, taking the time to do a self-assessment of the current situation can identify strengths and weaknesses in existing activities, approaches, public policies, or plans for improving population health. A self-assessment can be done using a formal process, an online tool, or even just by thinking through the 10 elements in this Guide.

Why it is important

Like a carpenter who first checks if he has the right tools to take on a new project, or an athlete who assesses her strengths and weaknesses to develop an effective training program, a self-assessment creates a foundation for understanding the current situation and environment. The assessment can highlight assets or capabilities, and reveal gaps or areas where there is a need for more resources or attention. Results of a self-assessment are important for making informed decisions when identifying key groups to participate in the work, setting goals and objectives, developing strategies, creating plans, then taking steps to move forward to achieve the desired results.

The steps to take after the self-assessment depend on what you learn from it. For example, if the assessment indicates that there has been little or no collaborative work in the region to improve health within or across the population, the next step might be to identify and bring together a small group of interested leaders to explore how to get started. In contrast, a self-assessment that reveals existing population health improvement projects in the region calls for bringing together the natural leaders to identify where new or stronger connections are needed. The assessment may also inform decisions about which organizations are well positioned to participate in a broader multistakeholder effort.

How it can be done

Such a self-assessment can be done informally as an initial individual review. It can also be done using a more structured and resource-intensive approach, which might involve research or gathering existing data; surveys or interviews of community members, key organizational partners, or other stakeholders; and other ways to gather information. There are also online tools to assist with self-assessments (see the resource links below). Just as there is no one correct way to approach the self-assessment, the questions to explore may differ by region. The questions may also differ depending on whether this is the first or the fifteenth time a self-assessment is being done.

For each of the elements in this Guide, any number of questions might be explored during a self-assessment. Questions can help to generate ideas or hypotheses about how best to approach the work, including where to start. The questions below are examples that can help kick-start the process.

- **A self-assessment about readiness to engage in this work:** What types of assessments have already been done in efforts to improve the health of this population?
- **Leadership across the region and within organizations:** Which individuals or organizations in the region are recognized or potential leaders in population health improvement?
- **An organizational planning and priority-setting process:** Which organizations in the region engage in collaborative planning and priority setting to guide activities to improve health in the region?
- **A community health needs assessment and asset mapping process:** Which organizations in the region already conduct community health needs assessments or asset mapping regarding population health?
- **An agreed-upon, prioritized set of health improvement activities:** What are the focus areas of existing population health improvement projects or programs, if any?
- **Selection and use of measures and performance targets:** Which measures, metrics or indicators are already being used to assess population health in the region, if any?
- **Audience-specific strategic communication:** What is the level of skill or capability to engage in effective communication with each of the key audiences in the region?
- **Joint reporting on progress toward achieving intended results:** Which organizations in the region publicly or privately report on progress in improving population health?
- **Indications of scalability:** For current or new population health work in the region, what is the potential for expansion into additional groups or other regions?
- **A plan for sustainability:** What new policy directions, structural changes, or specific resources in the region may be useful for sustaining population health improvement efforts over time?

After the self-assessment is done, the findings should help identify the next steps to take. For example, the self-assessment may indicate that it is not clear what is already happening in the region, so a basic mapping of assets would help identify existing population health improvement activities along with organizations or individuals who might be great potential partners. The results of the asset mapping could inform whether to start a new approach or instead focus on expanding or connecting existing activities.

After completing the self-assessment, the rest of the elements do not need to be followed in order. The elements should be addressed in a way that fits the regional situation. In addition, some elements, such as leadership and strategic communication, will be important throughout the process, updated and adjusted to adapt to the evolving situation.

The chart below offers one example. Under step one, a self-assessment (Element 1) is done. If this shows a lack of information about health improvement activities in a region, it may be useful during step two to map the assets in the region (Element 4) to identify organizations already involved in improving population health. This could also inform which leaders to invite to the table (Element 2) and require audience-specific strategic communication (Element 7). Then, in step three, an expanded group of committed participants defines the organizational planning and priority setting process (Element 3) and completes a broader community health needs assessment and asset mapping process (Element 4), while continuing to advocate for effective leadership and communication along the way.

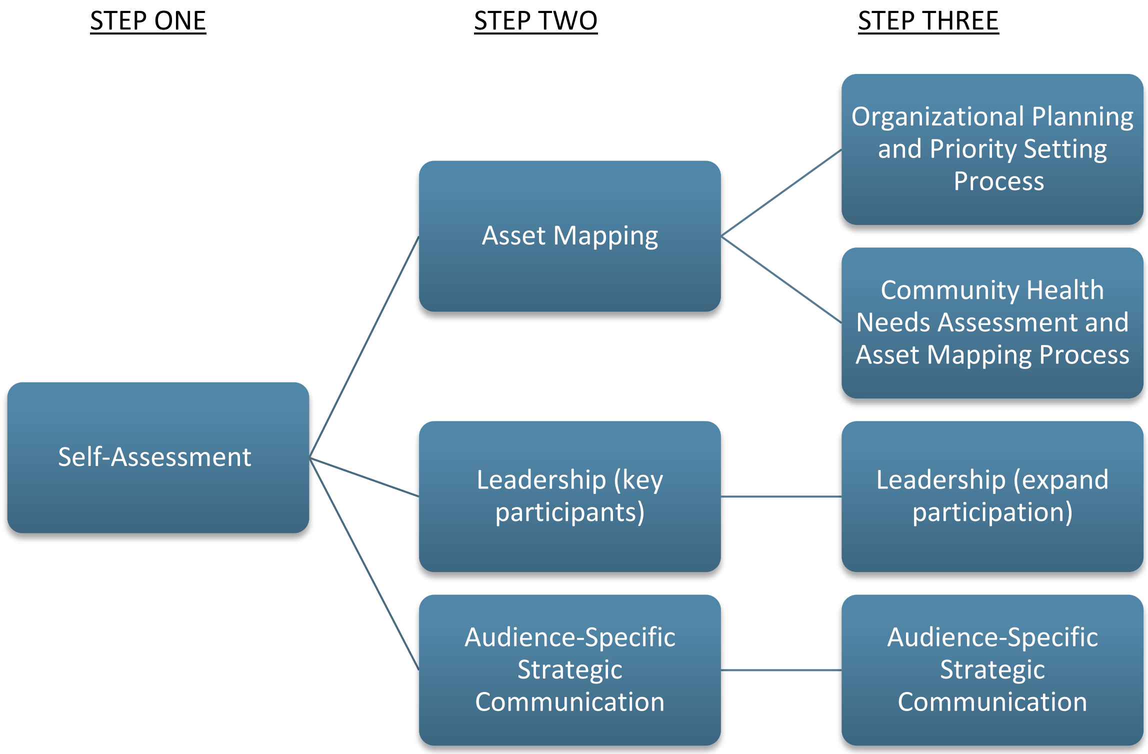

Figure 2. Example of Applying Self-Assessment to Determine Next Steps for Population Health Improvement

Element 2: Leadership Across the Region and Within Organizations

What it is

Simply put, leadership is the ability to guide or influence people. It is particularly important when bringing individuals and organizations together to accomplish a common task. Leadership has been the subject of study for centuries; it was part of the teachings of Confucius and Aristotle, even Sun Tzu's *The Art of War.* While the exact definition is still studied and debated, there are certain clear leadership skills and abilities. These include cultivating a shared and inspiring vision, thinking strategically, applying individual and collective intelligence, managing relationships and roles, using effective social skills in different situations, and being resilient, adaptable, and able to manage change over time. Leadership is important within an organization and across participating groups. Coalition leaders, for example, act as an integrator, playing the important quarterback role.

Improving population health requires leaders in several types of organizations and individuals to work together. **At a minimum, this should include representatives from public health, healthcare, and other key stakeholders who are strongly invested in the affected population.** The stakeholders who need to be involved may be diverse, such as consumer groups, local and state elected officials, tribal councils, Medicaid directors, business leaders, educators, transportation officials, housing advocates, community service providers, the military, corrections administrators, farmers, people with particular health conditions or disabilities, and the faith community.

In this type of work, leadership is more like putting together a complex puzzle, rather than directing the actions of others from the top of a pyramid.

Why it is important

Leadership is needed to bring this variety of groups together. Whether it is a single leader or a small group of people who inspire and guide others to get involved, creating this kind of momentum does not happen without one or more identified leaders at the helm. This requires skills in managing relationships and roles, strategy, and knowing how to find the right people and help them understand the benefit that they will get from participating. The organizations at the table will likely have differences in perspectives, organizational culture, terminology, and the value that they expect to get from the work. Leaders of such population health improvement initiatives must be able to build bridges across groups to create shared values and goals, while tapping into the unique motivations of the different organizations and individuals. Such leadership may be best done by a "trusted broker" who understands the importance of being an informed, yet neutral convener. Stakeholder organizations who are widely supported in a region and are recognized for their effective internal leadership may be natural candidates for taking on a broader leadership role.

Leadership is important at many levels. For example, each participating organization and individual shows leadership when they choose to take part in this work. In addition to building common ground among different groups, a crucial aspect of leadership takes place *inside* each organization involved. In other words, successful health improvement efforts involve people who are able to lead inside their own organizations to create an inspiring vision and promote understanding of the high priority of improving population health—and sometimes modify existing approaches to align their efforts with those of others.

The success of an effort like this depends on the engagement, commitment, involvement, and support (financial and otherwise) from each organization. This willingness to get involved in health improvement, and adapt as the work evolves, is important for activities that may include assessing health needs and identifying existing assets in the region (Element 4); engaging in specific health improvement activities that fit with each organization's focus and role (Element 5); supporting data collection and measurement (Element 6), and joint reporting on the progress being made (Element 8); and helping to expand (Element 9) and support the work over time (Element 10).

How it can be done, with examples

Listed below are examples of reports or initiatives that address this topic.

- **The YMCA's Pioneering Healthier Communities (PHC):** PHC teams take a "shared leadership" approach with community partners, which led to the revision of YMCA directives and activities based on a broader view of health. One of the seven leading practices that came from these relationships is the need to "adapt to emerging opportunities." http://www.ymca.net/sites/default/files/pdf/phc-lessons-leading-practices.pdf

- **Healthy Memphis Common Table:** This collaborative of community partners leads multiple population health improvement projects and oversees partnerships with around 1,000 individuals from 200 organizations in the community. Stakeholders run the gamut. They include individual consumers, schools, hospitals, physicians, nurses, nutritionists, dentists, and other healthcare providers, medical advocacy and support groups, insurance executives, health plans, quality improvement organizations, colleges and universities, businesses and employers, government including Medicaid, media, youth groups, faith-based organizations and churches, health-, fitness-, and recreation-related affiliates, and nonprofit agencies and foundations. Healthy Memphis Common Table serves as a convener, bringing disparate elements of the community together to take a comprehensive view of health. http://www.healthymemphis.org/af4q.php

- **The National Prevention Council:** Chaired by the Surgeon General, the National Prevention Council includes leaders representing 20 federal departments, agencies, and offices. The creation of the National Prevention Strategy and an action plan for its implementation led by this diverse group provides a solid example of how the federal government relied on leadership to bring together diverse perspectives and unite them around a common vision and specific prevention, health promotion, and public health goals. http://www.surgeongeneral.gov/initiatives/prevention/about/

Element 3: An Organizational Planning and Priority-Setting Process

What it is

An organizational planning and priority-setting process is the clearly defined approach that will be taken to define the goals, objectives, and activities of the population health improvement initiative — both within an organization and across organizations or groups that will come together in this work. This is not simply an acknowledgement that planning and priority setting will happen, but rather a deliberate step to define *how* the planning will be done and *how* the participating individuals and groups will identify priorities.

The process includes evaluation planning from the outset. Determining — up front — how you will assess, measure, and learn from the progress of the work over time will help define the path forward, and then guide decisionmaking and refinements along the way. Using clear approaches or models can inform how the evaluation is designed and implemented. This can include evaluating the program overall, measuring the success of key processes, assessing the impact of the work, and tracking changes in health outcomes over time. These issues are discussed further under Element 6.

Why it is important

Given the need to build and maintain trust with participating organizations, being transparent about *how* decisions are made is a necessary backbone of the work. Holding open meetings is one option for transparency, and establishing a unifying theme or focus for the different participants can be helpful to ground everyone in the same purpose for the overall work. In addition, achieving results is what motivates most people — that is, healthier individuals and populations, along with the related benefits of better health such as improved or sustained quality of life, lower healthcare costs, less absenteeism, better workplace productivity, and reduced financial impact affecting schools, community services, jails, and so on. However, the intended results will not be achieved if the participants are not clear about how the overall group expects to achieve collective impact, or if the decisionmaking process is perceived as unfair.

Some may want to jump into getting the work done to achieve better outcomes, rather than spending time up front defining the process. However, defining the way in which the groups at the table will make plans and set priorities, and then deliberately communicating how that process is being followed, is a core element of success. It is important to recognize and address the goals and motivations of each group during the planning process so that all participants feel invested in the work. Over time, modifications to the process being used are likely to be needed as the initiative matures and adapts to changing circumstances

In addition, evaluation is too often treated as an afterthought; this increases the likelihood of losing important information because it is not being captured while it is happening (or soon afterward). Incorporating evaluation into the process from the beginning also creates the opportunity to gather important information that will be useful for learning in real time to adapt and improve, and for making a compelling case to current and potential partners and funders.

How it can be done, with examples

Several models are available to use when defining and communicating the process that will be used for planning and setting priorities. For example, the table below offers criteria that can be applied when prioritizing population health problems, in addition to criteria to help choose actions to address the problem(s).

Table 1. Common Criteria for Prioritizing Population Health Problems and Interventions[26]

Criteria to Identify Top Priority Population Health Need(s)	Criteria to Identify Intervention(s) for Health Need(s)
• Impact of problem • Availability of effective evidence-based solutions • Cost and/or return on investment • Availability of resources (staff, time, money, equipment) to solve problem • Urgency of solving problem • Size of problem (e.g., number of individuals affected)	• Expertise to implement the solution • Return on investment • Effectiveness of the solution • Ease of implementation or maintenance • Potential negative consequences • Legal considerations • Impact on systems or health • Feasibility of the intervention • Ability to influence private and public policies (for example, through monetary incentives) that can sustain the intended impact

Other examples of prioritization approaches include: the multivoting technique; use of strategy grids; the nominal group technique; the Hanlon Method; and creating a prioritization matrix. These are all described in detail in a brief developed by the National Association of County and City Health Officials (NACCHO).[27] The brief includes step-by-step instructions on how to use these approaches, with examples and templates. There is no right or wrong method for prioritization. What works best should be tailored to fit the situation.

Part of this process should involve the review of national priorities, as there is clear emphasis being placed on promoting health in all policies and creating regulatory and financial incentives that reward those who improve individual and population health. Top priority areas, based on assessments of health needs across the country, are addressed in *Healthy People 2020* and the *National Quality Strategy* for example. To get the greatest possible impact, and maximize the potential benefits from alignment, consider where there are connections between the priority topics or needs identified through the needs assessments, asset mapping, and national priorities for health improvement.

Once prioritization has taken place, the next step is to plan solutions drawn from evidence-based interventions and recommendations, such as those offered in the Guide to Community Preventive

Services and National Prevention Strategy. Most planning models are cyclical, recognizing that these are not one-time activities but an ongoing process that should be designed to learn from what has already occurred and then adapted to improve the likelihood of success. Feedback loops are also a key feature, deliberately seeking out information or input, then using it to improve. A helpful model is the "Plan-Do-Study-Act" process, illustrated below.

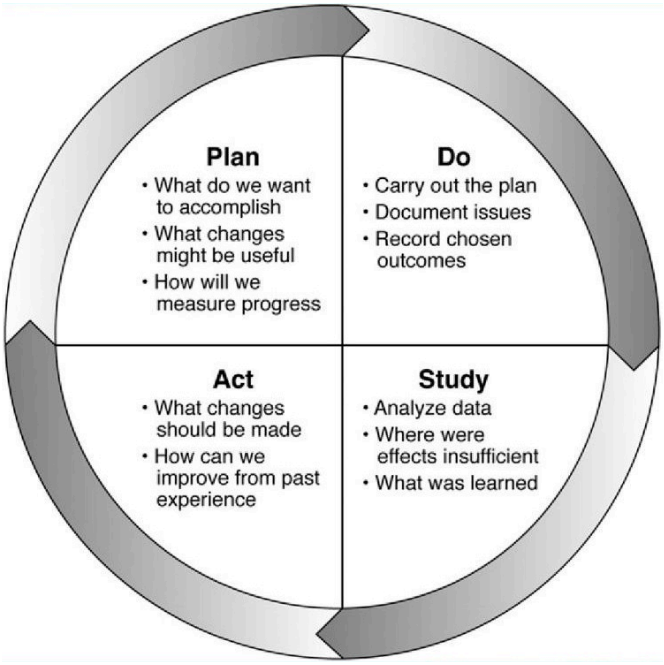

Figure 3. Plan-Do-Study-Act Cycle. Source: Medscape / AGA 2012

In each of the segments in the Plan-Do-Study-Act model shown above, there are steps that require more detailed thinking. For example, under the Plan step, when determining goals and changes that might be useful to improve health in your region, there are various ways to think about what actually impacts or drives health.

Listed below are additional examples of reports or initiatives that address this topic.

- **Mobilizing for Action through Planning and Partnerships (MAPP):** This is a community-driven strategic planning process for improving population health. It is a framework used by public health leaders and others to apply strategic thinking to prioritize public health issues and identify resources to address them. http://www.naccho.org/topics/infrastructure/MAPP/index.cfm

- **The National Service Frameworks:** This set of frameworks for improving care in various high-priority areas was developed by advisory groups from diverse fields, such as patient groups and nonprofit organizations. The frameworks determine research-based strategies and interventions, along with detailed processes for measurement and specific, timed targets. Each one is intended for use by all facets of the National Health Service (NHS) public health system, and as a resource for collaborative organizations spanning social services, community

institutions and more.
http://www.nhs.uk/nhsengland/NSF/pages/Nationalserviceframeworks.aspx

- **The Family Wellness Warriors Initiative:** This organization works one-on-one with Alaska-native communities to plan, implement, and assess a three-year-model aimed at reducing domestic violence, abuse, and neglect. The three-year model and curriculum were developed by a steering committee of Alaska-native people and mental health professionals, who worked on adaptation and development for two years by analyzing research-based evidence and projects from around the world.
  http://www.fwwi.org/index.cfm

Element 4: A Community Health Needs Assessment and Asset-Mapping Process

What it is

A community health needs assessment and asset-mapping process is a way to look at the current environment or situation in a region to identify any health-related gaps or needs and potentially helpful resources or strengths. Needs assessments typically involve defining the geographic focus or the region of interest (e.g., zip code, county, state, service area), collecting and interpreting data (e.g., population characteristics or demographics, health status), and identifying and prioritizing the health needs in that region, in part by engaging and learning from members of the community itself. Asset mapping is focused on the strengths or positive attributes of a region rather than deficiencies or needs. Assets can be tangible, such as financial strength, physical structures, businesses, or natural resources; or intangible, such as individual or organizational skills and capabilities, regional heritage, readiness for change that can lead to improvement, supportive public policy environment, resiliency and adaptability, or other special community characteristics or attributes.

While asset mapping and health needs assessments might be characterized as being separate and potentially at odds, they are complimentary and both need to be done. Health needs assessments and asset-mapping processes should be combined to create a shared understanding based on a more comprehensive view of the region. An important source of information for both is the members of a community itself: engaging the community to understand their perceptions and priorities. Both asset mapping and health needs assessments are important ways to listen and learn about what is already in place and what is needed.

Why it is important

Conducting a community health needs assessment and asset mapping helps ensure that the selected priority areas for population health improvement align with actual needs and make best use of resources. Doing this work as a larger collaborative of organizations, rather than developing competing reports, increases the likelihood of effectiveness, eliminates duplication of effort, reduces expenditures, and creates a shared understanding among all of the groups involved in the initiative. Learning from each other can be a powerful way to make more rapid progress.

Many groups have been conducting needs assessments for accountability and planning purposes. The use of community health needs assessments has been growing quickly and presents one of the most fertile opportunities for coordinated population health improvement efforts. Examples of existing or new incentives to conduct health assessments include:

- National accreditation for public health departments
- Program requirements of Federally Qualified Health Centers
- USDA support for schools to provide healthy nutrition for children
- Regional Extension Centers' need for assessments in rural areas
- Rules that govern nonprofit hospitals registered with the IRS as a 501(C)(3) organization

Each of these groups can partner with other sectors to achieve their goals. It will be important to align, rather than duplicate, efforts in order to form a solid foundation for effective collaboration without increasing the burden.

For example, there are nearly 3,000 nonprofit hospitals in the US, according to the American Hospital Association, and each hospital is affected by a new IRS requirement passed into law in 2010 as part of the Affordable Care Act. [28] It directs nonprofit hospitals to conduct a community health needs assessment once every three years — *in collaboration with public health entities and others* — and to develop and annually update a related "implementation strategy," which is an improvement plan with measurable goals and objectives. Starting in 2012, hospitals must conduct such assessments or pay a sizeable fine. While market competition may be a factor when there is more than one hospital in the same region, the IRS regulations, which are soon to be finalized, require a nonprofit hospital to consult with public health organizations and encourage collaboration with others in the same community, including other hospitals and medical systems.

In addition, the IRS has adopted a standardized nationwide reporting system (Schedule H filed with nonprofit hospitals' annual Form 990) that captures more complete information about the community benefit activities of each hospital, and includes a standard definition of "community benefit." Based on the IRS definition, nonprofit hospitals must engage in activities that include "community health improvement" work done by the hospital. Community benefit may include "community building" activities that have a direct connection to promoting the health of the population served by the hospital. Examples of activities that might qualify include physical improvements and housing; economic development; environmental investments; leadership development and training for community members; coalition building; community health improvement advocacy; and workforce development.[29]

With the new IRS requirement that nonprofit hospitals must engage in community health needs assessments and annual improvement plans, and report their population health improvement or community building activities, there is the potential for greater coordination of — and investment in — population health improvement aimed at meeting the specific needs in the region. It is also important to emphasize that other stakeholders such as health departments and community coalitions can play a very important role in the ultimate success of community benefit activities.

How it can be done, with examples

Listed below are examples of reports or initiatives that address this topic.

- **Assessing and Addressing Community Health Needs**: This was developed to help not-for-profit healthcare organizations strengthen their assessment and community benefit planning processes. The book offers practical advice on how hospitals can work with community and public health partners to assess health needs and develop effective strategies for improving health in their community. Among other resources, it includes ideas for data sources to understand the preferences and priorities of community members. http://www.chausa.org/communitybenefit/printed-resources/assessing-and-addressing-community-health-needs

- **Vermont Blueprint for Health:** As part of the implementation of the Blueprint, various workgroups and teams are created, including a Community Health Team and an Integrated Health Services workgroup, to assess specific needs and coordinate efforts within the community and in the clinical care field.
  http://hcr.vermont.gov/blueprint

- **DC Health Matters:** This community-driven, interactive web portal provides local health data, resources, best practices and information about local events to help community organizations and researchers understand and act upon health issues affecting DC communities. The database is a collaborative effort and a "living" project that continues to evolve as users contribute and share the information, which can be used to assess population health needs and assets. The website provides demographic, economic and health data for the communities of the DC area and includes report-creation tools.
  http://www.dchealthmatters.org (*Note: more than 100 communities have similar websites, based on the technology developed by the Healthy Communities Institute, which support continuous health improvement. Other examples include http://www.healthysonoma.org and www.sfhip.org*)

Element 5: An Agreed-Upon, Prioritized Set of Health Improvement Activities

What it is

An agreed-upon, prioritized set of health improvement activities is a list of strategies and actions that will be taken by organizations or individuals involved in population health improvement initiatives. This requires identifying the needs (see Element 4), agreeing what the focus areas will be, then defining the specific "ask" for each of the participants, such as commitment of staff time, financial resources, changes in private sector approaches or public policy, communications, etc. Be clear about what each group is being asked to do, and what the benefit or value proposition will be for each group in return for participating. Together, the organizations identify one or a few high priority topics for which they will lead health improvement activities in the region. The priority topic or topics are identified as a result of shared planning, assessment and decisionmaking. These priorities will drive the activities that each organization commits to doing with the people in the population or subpopulation(s) with whom they interact.

Why it is important

With so many factors that can influence health, even the best efforts of a solo project or program are at risk of having little impact. Population health is complex, involving multiple drivers and determinants, making it difficult for any one organization alone to make a measureable difference. This can lead to a sense that the problem is too big to solve and that improving individual health and the health of the population overall is beyond the control of any single organization or type of group.

Together, organizations can accomplish far more than any one could ever do alone. By collectively identifying one or a few top priority focus areas, and individually committing to engage in specific activities that promote improved health related to the focus, the collective initiative is much more likely to make an impact and see measureable improvement. This alignment also helps to create a shared awareness about the importance of the particular priority issue — whether that be reducing domestic violence or child abuse (or the incidence of any adverse childhood event), addressing depression and other mental health needs, reducing obesity, or promoting stronger social and family connections that are important to overall well-being.

How it can be done, with examples

After identifying top priority focus areas (Element 3), and drawing insights from the community health needs assessment and asset mapping process (Element 4), actions to address the priority topics or needs should then be considered in more detail. For example, a collaborative initiative called ReThink Health has developed a simulation model that can help groups predict the likely long-term effects of different activities, policy changes, financing, and other strategies on health outcomes, healthcare delivery, and costs. This can spur discussions about different options to address high priority needs.

Another way to identify potential actions is to identify contributing factors and likely causes for a given need or problem, and then use this information to drive potential solutions. This can be done using a "root cause map" like the one below for obesity.[30]

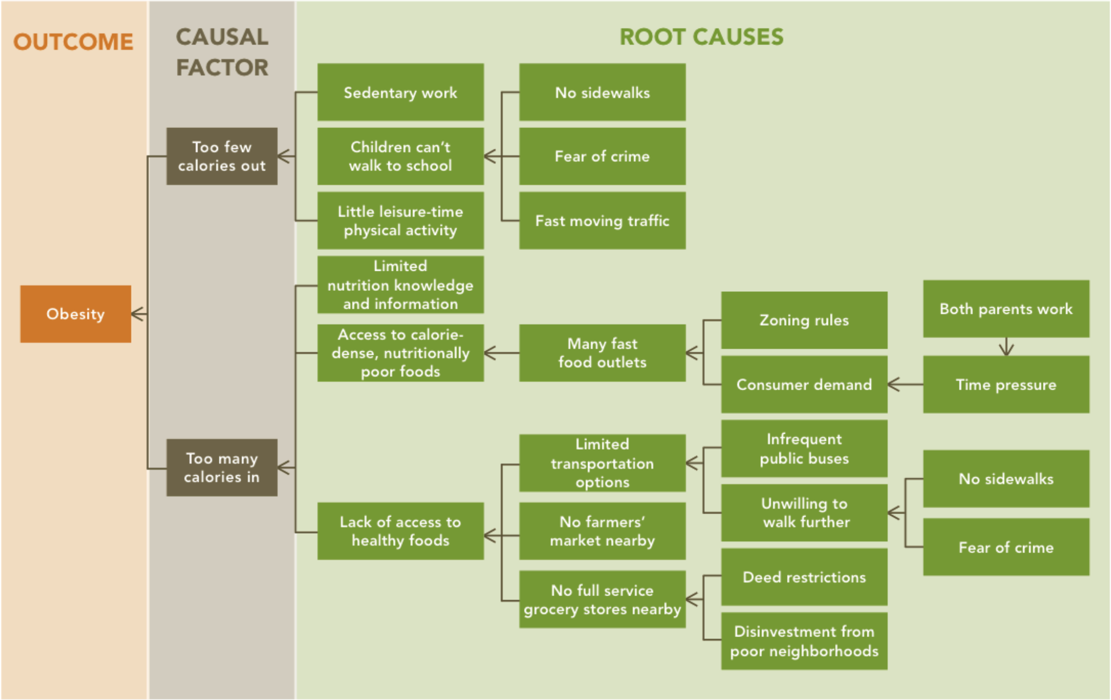

Figure 4. Root Causes of Obesity

Each outcome stems from causal factors, which can be traced to basic or root causes. Certain causes — stemming from genetics or biology, for example — may be difficult to address. On the other hand, root causes such as unsafe neighborhoods, poor access to affordable and healthy food options, a community ethic that tolerates unhealthy behavior, and so on, might illuminate possible actions or changes that can disrupt or eliminate the root cause of the poor health outcome. Sometimes efforts to address difficult problems need to start with small steps or a manageable "win" in order to build trust and a sense of shared accomplishment, enabling groups to take on more challenging issues over time.

Building on this example, if everyone agrees on a priority focus to reduce obesity in a region, a variety of activities could be identified for different organizations to commit to doing based on the root causes like those illustrated in the chart above. Such actions might include:

- *Employers — including public, private, and the military* — ensuring that salads and other nutritious foods are offered in the cafeteria and are more affordable than unhealthy options;
- *City planners and schools* working together to make neighborhoods around schools safer for biking and walking;
- *Hospitals, doctors, and nurses* measuring the body mass index (BMI) and discussing physical activity and better nutrition for all patients, since patients may be malnourished regardless of BMI;
- *Grocery stores* highlighting healthy food options in each aisle and offering cooking demonstrations of healthy recipes;

- *Community groups* starting a Saturday market where local farmers can sell fresh fruits and vegetables in underserved areas;

- *Churches and others in the faith community* organizing weight loss support groups through parish nurses and addressing obesity in the context of faith and spiritual health;

- And so on…

Listed below are examples of reports or initiatives that address this topic.

- **Healthy Base Initiative:** The aim is to assess best practices and lessons learned at 14 military bases selected by the DOD, to promote healthier and more resilient service members, families, retirees, and civilian employees.
  http://www.militaryonesource.mil/hbi

- **The Blue Zones Project:** The Blue Zones Project is an example of a community well-being improvement initiative designed to make healthy choices easier through permanent changes to the environment, policy, and social networks. The guiding principles are based on international research that identified nine healthy living principles in communities whose populations have achieved a high level of well-being and longevity. The project provides a framework for engaging public agencies, local business communities, schools, and a wide range of civic organizations in setting priorities and taking concrete actions to achieve a common goal of improving the well-being of the community.
  http://www.bluezonesproject.com

- **The National Prevention Strategy:** Since many of the strongest predictors of health and well-being fall outside of the healthcare setting, the National Prevention Strategy envisions a prevention-oriented society where all sectors contribute to the health of individuals, families, and communities. The Strategy identifies federal actions and provides evidence-based recommendations for a variety of partners (e.g., state and local governments, businesses and employers, healthcare systems and insurers, educational institutions, and community, non-profit, and faith-based organizations) to promote health across multiple settings. Priorities span clinical care delivery, community environments, and health behaviors, including: tobacco-free living, preventing drug abuse and excessive alcohol use, healthy eating, active living, injury and violence-free living, reproductive and sexual health, and mental and emotional well-being.
  http://www.surgeongeneral.gov/initiatives/prevention/strategy/

- **Let’s Move:** Let’s Move! is an executive initiative dedicated to solving the problem of childhood obesity. The program emphasizes that everyone has a role to play in reducing childhood obesity, and provides "5 simple steps" guides for parents, schools, community leaders, chefs, children, elected officials, and healthcare providers that give tips and strategies for adopting healthier lifestyles.
  http://www.letsmove.gov/

Element 6: Selection and Use of Measures and Performance Targets

What it is

Selecting and using measures and performance targets start with the process of identifying goals and measurable objectives that are relevant to the priority topics and associated health improvement activities. Part of the process should involve identifying relevant measures that are already in use by participating groups to periodically assess progress toward improving health and meeting performance targets. For any new measures, available data sources must also be identified. Some regions may choose to set rates of improvement as reasonable performance targets, or a specific level of performance such as "everyone should achieve a score of at least 90%." Others seek to exceed national or statewide benchmarks, such as the statewide average rate or the national top 10 percent.

Why it is important

The purpose of this work is to *improve* health across a population. Measuring progress, ideally against performance targets, is the only way to know whether the initiative is on track. Measurement against performance targets can also reveal when it's time to modify the approach in order to achieve better results. Measurement is one important part of evaluation, as described under Element 3.

Public- and private-sector leaders are increasingly using measures to hold certain types of organizations accountable for improving health outcomes, including public health agencies, healthcare organizations, and health plans. The accountability is also expanding into other sectors: consider "health in all policies" approaches that recognize the national imperative to improve health, understanding that health outcomes are affected by decisions and actions of a wide range of organizations and individuals. To meet accountability expectations, measurement is used to show that health outcomes are improving.

The state of available measures and data sources is an interesting mix of abundance, with hundreds of existing metrics and a vast array of data from many sources. Many organizations feel overburdened with measurement requirements, while others may be "drowning in raw data" but are not able to effectively apply this data for measurement and decisionmaking. The process of using many of the currently available data sources requires specialized skill and sufficient time to address problems such as finding the relevant data source; unlocking data that is available only in a "raw" format; and creating meaning from that data through analysis and visual presentation of the results in engaging, useful ways. Data must be translated into "actionable" information so that it can be used by leaders in public health, healthcare, and other sectors to assess and improve population health.[31]

NQF has endorsed 63 measures related to population health across varying levels of analysis, including healthcare providers and communities. These measures address the following topic areas:

- Health-related behaviors (e.g., smoking, diet) and practices that promote healthy living
- Community-level indicators of health and disease (e.g., incidence and prevalence) and community interventions (e.g., mass screening)
- Primary prevention and screening (e.g., influenza immunization)

There are also significant gaps in the measures available for population health improvement. Work is being done on a number of fronts to fill those gaps. For example, NQF is identifying and endorsing measures that focus on healthy lifestyle behaviors, community interventions that improve health and well-being, and social and economic determinants of health.[32] There is a strong interest in population-level measures that are appropriate for assessing shared accountability among a variety of sectors and organizations. Examples of measure topics that NQF is seeking for consideration for endorsement include:

- Health outcomes of individuals, including health/functional status, life expectancy, mortality, and quality of life
- Measures that assess the health of a total population or a subset of a population (subpopulation), including disparities across the population
- Measures that cover the lifespan, including those that focus on children, adolescents, and the elderly
- Adoption of healthy lifestyle behaviors
- Population-level measures in priority areas (e.g., obesity, physical activity, tobacco use, nutrition and diet)
- Receipt of health promotion and education services
- Social, economic, and environmental determinants of health with a clear connection to population health outcomes

NQF is providing guidance for measure developers to ensure a shared understanding of population health improvement and the related needs for new or modified measures. Such guidance recognizes that population health measures can reflect any point along the following continuum:

- Upstream factors that determine health, including socioeconomic, social norms, physical environment factors, and preventive health services
- Individual factors (i.e., behavior and genetics)
- Intermediate health outcomes (e.g., rates of disease and injury)
- Various states of health, including functional status
- Quality of life

Several types of measure gaps have been identified in NQF's prior projects, including the need for more outcome measures; population-level blood pressure screening measures for the Million Hearts Campaign; and composite measures that take into account process, outcome, access, structure, population experience, population management, population costs, and population services. Other areas of interest include measures with a focus on built environments; measures that assess patient and population health outcomes that can be linked to public health activities, such as improvements in functional status; assessments of community interventions to prevent elderly falls; and measures that focus on counseling for physical activity and nutrition in younger and middle-aged adults (18-65 years).

How it can be done, with examples

There is no universally recommended, practical set of population health measures for which there are widely available data sources. One helpful resource that may offer guidance will be available later in 2014 when the Institute of Medicine is expected to release a report with a core set of measures, including some expected to focus on population health improvement.

Given the dependence on available data and other differences among regions, the best approach may be to choose from a menu of relevant measures, and use what is possible now and expand over time. In other words, take a phased approach to measuring performance based on regional priorities and available data. Data sources continue to expand, in part due to increased reporting requirements and support for transparency in public and private activities. Advances in technology have enabled collection and sharing of de-identified healthcare data. New data sources are also appearing, such as consumer-generated data drawn from discussions on social media.

Among measures to use, consider disparities-sensitive measures to assess differences in health status or outcomes for ethnic or racial groups, and other vulnerable populations. These measures can be used to detect differences in quality across settings or in relation to certain benchmarks, and differences in quality among populations or social groupings based on race, ethnicity, language, and other characteristics.

Taking a practical approach is necessary. Identify measures already in use, any new measures needed to fill gaps, and the basic data available for the region. For data, use sources that are high-quality, relevant, understandable, and timely, if possible. Over time, what may start as a short list of population health measures will undoubtedly become more robust as the field evolves.

Drawing from a previous assessment of 26 reports that evaluate population health improvement, the following chart lists the most common measures and indicators that were used, grouped by topic or domain.[33]

Table 2. Example of Population Health Measures by Topic

Topic / Domain	**Measures / Indicators**
Health status / health related quality of life (total population level)	• Life expectancy • Healthy life expectancy • Years of potential life lost • Healthy days (physically, mentally) • Self-assessed health status • Expected years with activity limitations • Expected years with chronic disease
Health outcomes **Ultimate / final (total population level)**	• Mortality (death rates) • Morbidity (e.g., disease or injury rates, obesity rates, mental health) • Pregnancy and birth rates • Health status and health-related quality of life
Health outcomes **Intermediate (total population level)**	• Levels of risk behaviors (e.g., diet, physical activity, tobacco use, alcohol/drug use) • Rates of access to, use of, and coverage of preventive services (e.g., cancer screening, immunizations, weight loss intervention, smoking cessation) • Physiologic measures (e.g., controlled blood pressure or cholesterol levels)
Determinants of health (total population level)	
Social environment	• Poverty level • High school graduation rates • Exposure to crime and violence, neighborhood safety • Affordable and adequate housing
Physical environment	• Built environment (transportation options, availability of healthy foods, recreational facilities and parks, neighborhood walkability) • Exposure to environmental hazards (air, water, food safety) • Natural environment (e.g., access to green space, protection from natural disasters)
Clinical care	• Access to healthcare services and insurance coverage • Unmet health needs or delayed care
Behaviors	• Rates of tobacco use, alcohol misuse, physical inactivity, and unhealthy diet

Table 2. Example of Population Health Measures by Topic (continued)

Topic / Domain	Measures / Indicators
Health improvement activities – capacity, process, and outcomes (subpopulation level)	
Capacity	• Electronic health records and integrated surveillance systems • Preparedness surge capacity and response times
Processes	• Materials translated, health literacy • Quality improvement projects • Effective and efficient care coordination and case management • Adherence to health promotion or treatment advice • Levels of risk behaviors (e.g., diet, physical activity, tobacco use, alcohol/drug use) • Rates of access to, use of, and coverage of preventive services (e.g. cancer screening, immunizations, weight loss intervention, smoking cessation) • Physiologic measures (e.g., controlled blood pressure or cholesterol levels)
Outcomes	• Preventable hospitalizations and readmissions • Patient satisfaction • Timely and appropriate care received

Element 7: Audience-specific Strategic Communication

What it is

Audience-specific strategic communication means customizing messages and approaches in ways that connect with the target audiences. This is essential for all aspects of this work — across the organizations participating in the population health improvement work, with individuals and groups affected by it, and with others, such as elected officials or other policymakers, whose decisions directly affect health determinants. Although the vision and goals of the initiative should stay consistent, the content, style and even the method of communication may need to be adapted to speak to the values, priorities, and cultural filter of the intended audience. This requires cultural humility on the part of the communicator—understanding that what is intended may not always be what is heard. The goal of audience-specific strategic communication is to understand the perspective of others, then communicate in ways that reflect that understanding.

Why it is important

Effective communication can make or break this work. As described in Element 2, the wide range of organizations and individuals who have a role in improving health means that communication must take place in ways that span different cultures, terminology, goals, and values. Addressing differences across audiences requires culturally sensitive interaction, and is at the heart of strategic communication. This is important to engage and motivate partners to collaborate and work well with external groups.

How it can be done, with examples

Many sectors use unique terminology that can be confusing, and this is especially true in healthcare and public health. Using words that are easy for everyone to understand, explaining commonly misunderstood terms, and avoiding acronyms are a few basic principles to follow.

Communication that works for one group will not work for everyone. For example, some individuals and organizations are driven by business principles and will look for the value proposition and evidence of likely return-on-investment in any initiative. Understanding that time and financial resources are limited, and cost reduction is imperative, these groups will respond to discussions about improving health at the population level if there is a compelling business case. At the same time, some individuals and organizations engage in population health improvement because it reflects social values such as equity and fairness, dignity, and opportunity. In this case, discussing population health improvement using business-oriented perspectives and terminology may not be as effective.

Listed below are examples of reports or initiatives that address this topic.

- **Health in All Policies**: Exploring a collaborative approach to improving population health, “Health in All Policies” offers guidance for state and local governments on incorporating health considerations into diverse sectors of public policy. The glossary includes a comprehensive and generally applicable list of terms that spans health, business strategy, environmental planning, sociology, and policy. See specific communication guidance starting on page 101. http://www.phi.org/resources/?resource=hiapguide

- **HHS Action Plan to Reduce Racial and Ethnic Disparities:** This outlines the goals and actions that the U.S. Department of Health and Human Services (HHS) will take to reduce health disparities among racial and ethnic minorities, including making a strong case for providing culturally sensitive communication and care. http://www.minorityhealth.hhs.gov/npa/templates/content.aspx?lvl=1&lvlid=33&ID=285

- **White Earth Nation Tobacco Coalition:** This action plan to reduce commercial tobacco use in the tribal community of White Earth in Minnesota focuses on culturally relevant outreach materials and policy guides to provide information about the effects of smoking and its cultural impact on the tribe. Materials are aimed at individuals, healthcare providers, and community institutions, and include the use of language specific to the tribal community, such as use and explanation of the word “Asayma” to mean “sacred tobacco.” http://www.whiteearth.com/programs/?page_id=405&program_id=4#Tobacco

- **Family Wellness Warriors Initiative (FWWI):** This initiative involves working with communities to implement a three-year model designed for Alaska-Native areas. The model was developed by a group of 30 stakeholders, including Alaska-Native people and mental health professionals, who researched internationally for programs pertaining to domestic violence and abuse. The model is designed for scalability within Alaska-Native areas, since it is designed specifically to be

culturally relevant to these communities.
http://www.fwwi.org/index.cfm

- **Primary Care and Public Health: Exploring Integration**: This report recognizes and attempts to bridge differences in the cultures of medical and public health systems. Examples include charts that contrast areas such as training approaches, perspective in levels of analysis, and funding sources.
http://www.iom.edu/Reports/2012/Primary-Care-and-Public-Health.aspx

Element 8: Joint Reporting on Progress Toward Achieving Intended Results

What it is

Joint reporting on progress toward achieving the intended results is a way for the participating groups and organizations to share insights from the needs assessment and asset mapping (Element 4), the evaluation of activities (Element 3), and the use of measures and performance targets (Element 6).

Why it is important

Joint reporting establishes the accountability of each organization to the others in the initiative. In addition, pulling together the results for actions across the initiative (described in Element 5) and sharing that information with all participants keeps everyone informed about the progress of the work and creates common ground for shared learning. It also helps to identify where greater collaboration might be needed to improve results. This reporting should align with the areas of evaluation that are part of the planning and priority-setting process (Element 3), to reinforce the shared commitment to achieving the intended results at a variety of levels.

How it can be done, with examples

In addition to health outcomes, the content of such reports might address impact on social values or perceptions about health, return on investment, and elements that indicate the progress of the overall initiative. Such reporting might typically begin as private sharing of results among the collection of participating organizations, either reported individually or developed as a single report about the collaborative and individual efforts. Given the importance of transparency and accountability, ultimately the goal is to share the progress reports with the general public.

Listed below are examples of reports or initiatives that address this topic.

- **Primary Care and Public Health – Exploring Integration to Improve Population Health:** The Institute of Medicine identifies a set of core principles derived from successful integration efforts that involve the community in defining and addressing needs for population health improvement. The framework emphasizes that the collection and use of data to assess needs and progress is important to the integration process, and that sharing data appears to be a natural way in which primary care and public health can work together.
http://www.iom.edu/Reports/2012/Primary-Care-and-Public-Health.aspx

- **Hennepin Health:** This pilot program uses an integrated data warehouse and analytics infrastructure to support timely, actionable feedback to members, providers, and administrators and to align metrics across medical care, public health, and social service providers. Metrics specifically address goals to reduce hospitalizations; increase compliance to keep chronic diseases in control; reduce emergency department visits; reduce detox utilization; assist with a safe and stable living situation; increase functional skills/independence; decrease substance abuse; decrease health risk factors; assist with a healthy natural support system; and maintain Medicaid eligibility for each enrollee.
  http://www.hennepin.us/healthcare

- **National Health Service Care Data:** While the National Health Service (NHS) in the United Kingdom has collected and used hospital data for the last few decades as part of its national database, a new initiative aims to expand the amount of information available to patients, clinicians, researchers, and planners. The NHS claims that "better information means better care" and will ensure consistency in quality and safety, and highlight areas where more investment is needed.
  http://www.england.nhs.uk/ourwork/tsd/care-data/

Element 9: Indications of Scalability

What it is

Scalability is the ability for an initiative to expand, either by becoming more deeply involved in the region — for example, increasing the number of participating organizations or taking on new priority topics and related health improvement activities — or by sharing the lessons learned with others to motivate spread to additional regions. The latter can happen either as the initiative grows geographically, or when a new group learns from the work and decides to take a similar approach. Scalability or expansion of initiatives to new areas is not guaranteed and does not always happen even when the evidence is clear that a program has achieved intended, positive results.

Why it is important

Poor health is a problem everywhere in the United States. To the degree that existing health improvement efforts are refined and new successful initiatives started, from which others can learn then adopt in their own region, this expands the possibility for achieving better health for more people. That being said, achieving traction in other regions may not always be possible, especially if the population health improvement work relies on assets or characteristics that are unique to a region.

How it can be done, with examples

During the planning process (Element 3), consider and emphasize activities that can be easily expanded or adopted by others. At the same time, during the asset mapping process (Element 4) consider which assets might be unique to either one subpopulation or to a smaller geographic part of the whole geopolitical area. These unique assets may limit the ability to spread the initiative across the entire population and/or geopolitical region.

Listed below are examples of reports or initiatives that address this topic.

- **Camden Care Management Program and Cross-Site Learning:** This program was developed by the Camden Coalition of Healthcare Providers started in Camden, New Jersey, using data to target and coordinate care for patients who lack consistent primary care and often suffer from chronic illness, mental illness, and substance use disorders. The Cross Site Learning program is now being implemented in 10 cities. http://www.camdenhealth.org/cross-site-learning/

- **Healthy Communities Institute (HCI):** This organization provides customizable, web-based information systems to visualize the best-available local data through indicator dashboards and GIS maps. The Healthy People 2020 Tracker helps evaluate the effectiveness of the local group's programs and the health of the community compared to national goals. HCI websites have been replicated across the country. http://www.healthycommunitiesinstitute.com/

- **State Innovation Models Initiative:** This initiative led by the Centers for Medicare & Medicaid Services (CMS) is intended to foster the testing and development of state-based models for improving health system performance through multipayer payment reform and other system changes. The projects are broad-based and focused on enrollees of Medicare, Medicaid, and the Children’s Health Insurance Program (CHIP). The initiative is exploring models that could form a foundation for expansion into larger health system transformation. http://innovation.cms.gov/initiatives/state-innovations/

Element 10: A Plan for Sustainability

What it is

Sustainability is the ability to continue operating, funding the work, and remain productive over time. In addition to developing a sustainable business model, adaptability and resilience are key characteristics of sustainable initiatives.

Why it is important

In the current policy environment, health improvement has gained new relevance: poor health outcomes are widely understood as a major problem, coupled with unsustainable healthcare costs. Population health improvement is a complex field, and although public

Examples of How Changes in Public Policy Can Sustain Conditions that Promote or Support Health

- ✓ Tobacco use prevention and cessation is promoted with smoke-free workplaces and public places.
- ✓ Physical activity for children increases under policies that allow and promote safe routes to schools and open school recreation areas for after-school community use.
- ✓ Establishing farmers markets is possible once land use planning policies allow for such activities.
- ✓ Access to healthy foods and beverages improves when school vending machine policies follow nutrition guidelines.

health agencies and others have been working to improve population health for years, the only way to achieve a lasting positive impact is through multifaceted, sustainable approaches that address health improvement in activities across all of the determinants of health over the long term.

How it can be done, with examples

Developing a sustainability plan or a business plan based on a sustainable model is the most effective approach. Knowing what approaches can be continued over the long run, with appropriate support and financial stability, is not an easy task. For example, receiving a multiyear grant or being funded through a government project are likely no substitute for a solid sustainability plan, as even multiyear grants and government programs eventually come to an end.

Opportunities exist given the rapidly changing health policy environment. When engaging in population health improvement, the ability to motivate structural changes can increase the likelihood that the change will be sustained. Examples include new or revised commitments (e.g., public or private policy or contract provisions that incentivize better health or incorporate health in all policies), new patterns of care and coordination among different organizations, and linking medical and public health information systems. Examples of new policy opportunities include structures being developed or implemented such as Accountable Care Organizations, Accountable Health Communities, Patient Centered Medical Homes, community health improvement requirements for nonprofit hospitals (see Element 4), and Public Health Accreditation.

While activities that encourage changes in public or private policy sometimes involve political advocacy, this is not always the case. An example of a private-sector policy change is to support employers in encouraging employees to make use of covered preventive services and smoking cessation programs. Employers could also begin assessing and reporting (Element 8) the degree to which their employee population is using such benefits.

Listed below are examples of reports or initiatives that have successfully addressed this topic.

- **Health in All Policies:** The Health in All Policies guide for state and local governments defines sustainability as “the need of society to create and maintain conditions so that humans can fulfill social, economic, and other requirements of the present without compromising the ability of future generations to meet their own needs.” The document focuses on environmental sustainability as an essential part of ensuring the longevity of health improvement plans, with examples referenced throughout.
http://www.phi.org/resources/?resource=hiapguide

- **A Healthier America 2013: Strategies to Move from Sick Care to Health Care in Four Years:** This guide for improving the nation’s health system focuses on various strategies and priorities for achieving sustainability, in addition to recommendations for shifts in governmental funding. Suggested policies include ensuring sufficient and stable funding for public health departments, with recommendations to explore new funding models based on supporting basic capabilities.
http://healthyamericans.org/report/104/

- **Correctional Health Outcomes and Resource Dataset (CHORDS):** CHORDS is a quality improvement initiative attempting to address the long-term health status of the incarcerated population, which involves a high-need, high-cost public structure that is guided by public policy and funded with taxpayer dollars in every state. CHORDS offers a national performance measurement and data sharing system within corrections. The project focuses on benchmarking to enhance the quality and effectiveness of care across the correctional healthcare system. http://www.ncchc.org/chords

- **Moving Healthy:** The U.S. Department of Transportation Federal Highway Administration (FHWA) has set out policy guidelines to ensure the integration of health-related considerations in the planning and execution of its programs. The FHWA claims that health is implicit in transportation, and the agency has a responsibility to ensure the promotion of positive health outcomes and the mitigation of negative health outcomes through the programs and resources it provides, such as safe and accessible facilities for biking and walking. https://www.fhwa.dot.gov/planning/health_in_transportation/resources/moving_healthy.cfm

- **The Guide to Community Preventive Services:** The Community Preventive Services Task Force (Task Force) was created by the HHS to determine which interventions work for improving population health in various settings. Recommendations of the Task Force are available in the Guide to Community Preventive Services, a free resource to help identify programs and policies to improve health and prevent disease in the community. Systematic reviews are used to explore program and policy interventions, effective interventions for specific communities, and the cost and potential return on investment of interventions. http://www.thecommunityguide.org/index.html

Conclusion

This draft Guide v1.0 is the first step toward developing a practical handbook — which may become an online resource in the future — and is intended to be short, with links to more information and useful resources. It takes a broad look at the issue, without duplicating the great work already done by others. Moving forward, pending continued support of this work by HHS into the second year, the Guide v1.0 will be shared with the project committee of experts, the public, and selected groups engaged in population health improvement who volunteer to review, apply, and help refine the Guide v1.0. These groups will help answer questions such as:

1. What would make the Guide more useful, if anything?
2. Which of the 10 essential elements are most helpful, and why?
3. What types of examples might still be needed to help illustrate topics that are unclear or particularly challenging?
4. Are there any changes you would recommend to the lists of resources to make them more practical for the work you are doing? (Please see Appendices B, C, D, and E.)

5. Do the actions suggested in this Guide align with your organization's goals and values? Why or why not?

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Appendix A: Methodological Approach

This is the first draft version of the Guide, developed with the intention to gather input from the project committee of experts and the public. The comments on the name and content of this document will be used to refine the Guide (version 1.0 or v1.0).

Pending continued support of this work by the Department of Health and Human Services into the second year, the Guide v1.0 will be shared with the project committee of experts, the public, and selected groups engaged in population health improvement who volunteer to review, apply, and help refine the Guide v1.0. The project team will regularly interact with these selected Field Test Groups to learn from their implementation activities associated with the Guide v1.0. Requested input on the Guide will focus on both the content and the format (e.g., written report with hyperlinks, online site, interactive application), driving modification of the Guide to be more specific and practical at the local, state, and national levels. The refinements will be included in the second version of the Guide (v2.0).

The third year of this project will involve the development of the final version of the Guide (v3.0). During this year, various iterations will be shared with the project Committee of experts, the public, and the Field Test Groups to gather additional input on the content and format. This guidance will be used to finalize the Guide.

This draft Guide v1.0 builds on insights from the following sources:

- NQF Population Health Framework Committee, a multistakeholder committee of experts providing guidance regarding the development of the Guide. For the roster of committee members and a summary of their activities, go to http://www.qualityforum.org/projects/population_health_framework.

- *Multistakeholder Input on a National Priority: Working with Communities to Improve Population Health. Environmental Scan and Analysis to Inform the Action Guide*, developed by a project team at NQF in 2013. This paper assessed key elements in conceptual frameworks in academic papers and articles, in addition to core aspects of programs being implemented at the local, state, or national levels, to identify insights regarding potential content for the *Action Guide*.[1]

- *An Environmental Scan of Integrated Approaches for Defining and Measuring Total Population Health*,[2] commissioned by NQF in 2012. Jacobson and Teutsch established definitions for key concepts and a list of recommendations that provided a starting point for this environmental scan, including criteria that were used to assist with selection of the 40 frameworks and initiatives addressed in this report. Given the tremendous amount of research and thousands of programs focused on population health improvement, this report was designed to gather a representative range of examples that present a strong cross-section of insights.

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[2] Jacobson DM, Teutsch S*. An Environmental Scan of Integrated Approaches for Defining and Measuring Total Population Health by the Clinical Care System, the Government Public Health System, and Stakeholder Organizations*. Washington, DC:NQF;2012. Available at http://www.qualityforum.org/WorkArea/linkit.aspx?LinkIdentifier=id&ItemID=70394. Last accessed July 2014.

Appendix B: Links to Helpful Resources

Listed below are the 10 elements and, for each, a few links to single sources of additional information, tools, and other resources about the element topic. Other sources may be just as useful, and these may change over time, but this should be a good place to start.

Element 1: Resources for Self-Assessment of Readiness to Engage in this Work

- **County Health Ranking and Roadmaps– Tools and Resources:** This Robert Wood Johnson program provides a database and a large number of tools to help assess readiness and the resources and needs of your region.
  http://www.countyhealthrankings.org/resources?f[0]=field_global_action_steps%3A18389

- **Are You Ready to Pursue the Triple Aim?**: This is an online assessment provided by the Institute for Healthcare Improvement intended to help health-related organizations or systems, or coalitions of organizations working to improve health and healthcare, get ready to pursue the Triple Aim — including population health improvement.
  http://www.ihi.org/Engage/Initiatives/TripleAim/Pages/TripleAimReady.aspx

- **Community Commons – Community Health Needs Assessment Toolkit**: This toolkit is a free web-based platform designed to help hospitals and organizations understand the needs and assets of their communities, and work together to make measurable improvement in population health.
  http://assessment.communitycommons.org/CHNA/

Element 2: Resources for Leadership Across the Region and Within Organizations

- **Pioneering Healthier Communities — Lessons and Leading Practices:** This document shares the seven “leading practices” learned through YMCA initiatives and explains how other organizations can implement these principles.
  http://www.ymca.net/sites/default/files/pdf/phc-lessons-leading-practices.pdf

- **Working Together, Moving Ahead: A Manual to Support Effective Community Health Coalitions**: This handbook is designed to support those who participate in coalitions, provide staff support to coalitions, provide funding or in-kind resources to coalitions, or require their grantees to organize and utilize coalitions in their work. It provides practical advice on common concerns and problems facing coalitions. The manual aims to get people thinking about why they have chosen to use coalitions in their work, about their assumptions in building coalitions, and about the structures and processes they are using with coalitions.
  http://www.policyarchive.org/handle/10207/21720

- **Community How-To Guide on Coalition Building:** This guide from the National Highway Safety Transportation Administration provides guidance on bringing together a diverse group of people in pursuit of a common goal. The guide is part of a set to assist with underage drinking prevention efforts; however, the information is not topic-specific and can be applied to various population health improvement projects. http://www.nhtsa.gov/people/injury/alcohol/Community%20Guides%20HTML/Guides_index.html

- **County Health Rankings and Roadmaps:** The “Action Cycle” includes an interactive graphic exploring the various stakeholders that should be included in population health projects, along with guidance on how to connect and work together. http://www.countyhealthrankings.org/roadmaps/action-center

Element 3: Resources for an Organizational Planning and Priority-Setting Process

- **Guide to Measuring the Triple Aim: Population Health, Experience of Care, and Per Capita Cost:** This 2013 white paper from the Institute for Healthcare Improvement offers a useful logic model for considering drivers of health, with related examples for measuring population health. http://www.ihi.org/resources/Pages/IHIWhitePapers/AGuidetoMeasuringTripleAim.aspx

- **Practical Playbook:** The “Stages of Integration” framework encourages organizational planning and offers guidance on the process. https://practicalplaybook.org/stages-integration

- **County Health Rankings and Roadmaps:** The “Roadmaps” framework provides guidance on the organizational planning process and how to determine priorities. http://www.countyhealthrankings.org/roadmaps/action-center/focus-whats-important

- **Plan, Do, Study, Act (PDSA):** The PDSA model has been utilized by the National Health Service in the United Kingdom to encourage trials of new policies before implementation. The model consists of four recommended steps to test an idea and assess its impact: planning the change to be tested or implemented (Plan); carrying out the test or change (Do); Studying data from before and after the change and reflecting on what was learned (Study); and planning the next change cycle or full implementation (Act). http://www.institute.nhs.uk/quality_and_service_improvement_tools/quality_and_service_improvement_tools/plan_do_study_act.html

- **ReThink Health**. This suite of interactive tools opens up new ways of looking at population health improvement. The intention is to guide leaders in considering the impacts of different policies and interventions and make better and more creative decisions about redesign. http://rippelfoundation.org/rethink-health/dynamics/

Element 4: Resources for a Community Health Needs Assessment and Asset Mapping Process

- **ACHI Community Health Assessment Toolkit:** The toolkit provides detailed guidance on six core steps of a suggested assessment framework, including, but not limited to, data collection. http://www.assesstoolkit.org/

- **Asset Mapping from the Southern Rural Development Center:** This article explains a process for mapping the assets of a community and provides guidance on collaborating with various organizations and individuals with the goal of community development and enhancement. The article offers an overview of the needs assessment process and then a step-by-step work plan for each element of the model.
  http://www.nebhands.nebraska.edu/files/227_asset_mapping.pdf

- **County Health Rankings and Roadmaps:** The "Assess Needs and Resources" section of the "Roadmaps" framework provides guidance on taking stock of your community's needs, resources, strengths, and assets.
  http://www.countyhealthrankings.org/roadmaps/action-center/assess-needs-resources

- **Practical Playbook:** The "Stages of Integration" framework encourages public health entities to analyze the most recent community health needs assessment to identify population health projects. The framework also offers guidance on the prioritization process and how various entities can work together to identify needs in the community.
  https://practicalplaybook.org/stages-integration

- **Regional Equity Atlas 2.0 and Action Agenda:** This population health improvement tool maps the intersection of chronic disease prevalence data and data on the social, economic, and physical determinants of health for the Portland metro region, providing insight into key findings. As a resource, the Regional Equity Atlas has been used by various AF4Q projects to identify target areas for health improvement in specific geographic areas. http://clfuture.org/equity-atlas

- **Community Commons – Community Health Needs Assessment Toolkit**: This toolkit is a free web-based platform designed to assist hospitals and organizations understand the needs and assets of their communities, and work together to make measurable improvement in health in the community. http://assessment.communitycommons.org/CHNA/

- **Resources for Implementing the Community Health Needs Assessment Process**: This set of resources from the CDC helps to translate the requirements of the Affordable Care Act, with the intent to encourage active engagement between hospitals and public health.
  http://www.cdc.gov/policy/chna/

Element 5: Resources for an Agreed-Upon, Prioritized Set of Health Improvement Activities

- **The Guide to Community Preventive Services:** The Community Preventive Services Task Force (Task Force) was created by the Department of Health and Human Services to determine which interventions work for improving population health in various settings. Recommendations of the Task Force are available in the Guide to Community Preventive Services, a free resource to help identify programs and policies to improve health and prevent disease in the community. Systematic reviews are used to explore program and policy interventions, effective interventions for specific

communities, and the cost and potential return on investment of interventions.
http://www.thecommunityguide.org/index.html

- **A Compendium of Proven Community Based Prevention Programs**: This report from The Trust for America's Health and the New York Academy of Medicine highlights nearly 80 evidence-based prevention programs that have been proven to improve health and save lives. Topics addressed include tobacco use reduction, asthma, injuries, sexually transmitted infections, alcohol abuse, physical activity and eating habits.
  http://healthyamericans.org/assets/files/Compendium_Report_1016_1131.pdf

- **County Health Rankings and Roadmaps**: The "What Works for Health" database includes health improvement activities from the Guide to Community Preventive Services as well as other population health topics.
  http://www.countyhealthrankings.org/roadmaps/what-works-for-health

Element 6: Resources for Selection and Use of Measures and Performance Targets

- **Population Health Measures Endorsed by NQF:** This list or portfolio of measures contains measures which have been identified by the National Quality Forum as being relevant for population health measurement.
  http://www.qualityforum.org/QPS/QPSTool.aspx?p=3863

- **Disparities-Sensitive Measures Endorsed by NQF:** This subset of measures are those which have been identified by the National Quality Forum as being appropriate for assessing disparities, within the population health measure portfolio.
  http:/www.qualityforum.org/QPS/QPSTool.aspx?p=3865

- **Health Indicator Warehouse:** This online library provides access to national, state and community health indicators. It serves as the data hub for the HHS Community Health Data Initiative and is a collaboration of various agencies within the department. The Health Indicator Warehouse is referenced by the County Health Rankings and Roadmaps program as a resource for those working on population health projects.
  http://healthindicators.gov/

Element 7: Resources for Audience-specific Strategic Communication

- **County Health Rankings and Roadmaps:** The "Action Center" framework provides guidance on effective communication.
  http://www.countyhealthrankings.org/roadmaps/action-center/communicate

- **Disseminating Relevant Health Information to Underserved Audiences: Implications of the Digital Divide Pilot Projects:** This paper examines the digital divide and its impact on health literacy and communication. The digital divide can be a significant impediment in health literacy and information

dissemination.
http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1255755/

- **Simply Put: A Guide for Creating Easy-to-Understand Materials:** This resource from the Centers for Disease Control and Prevention (CDC) offers insight on how to use plain language, visuals, clear formatting, and cultural sensitivity to communicate effectively with health-related materials.
http://www.cdc.gov/healthliteracy/pdf/simply_put.pdf

- **YMCA Pioneering Healthy Communities:** This is a practical toolkit that includes a useful framework for considering how to communicate effectively, using culturally respectful plain language.
http://www.ymca.net/healthier-communities

Element 8: Resources for Joint Reporting on Progress Toward Achieving Intended Results

- **County Health Ranking and Roadmaps:** This resource shows results for a number of measures and indicators by county across the United States, and clearly describes their methods for developing the rankings that are reported.
http://www.countyhealthrankings.org/Our-Approach

- **The Network for Public Health Law: Checklist of Information Needed to Address Proposed Data Collection, Access and Sharing:** This tool provides a checklist to assist public health practitioners in providing relevant factual information to address issues of legality, privacy, and ethics.
https://www.networkforphl.org/resources_collection/2014/01/07/400/tool_checklist_of_information_needed_to_address_proposed_data_collection_access_and_sharing

Element 9: Resources for Indications of Scalability

- **Let's Move Initiative:** This national initiative focused on reducing childhood obesity uses its website as a tool for sharing best practices and promotional material that others can use. The initiative has encouraged "Let's Move Meetup" programs in more than 400 cities nationwide, where community members get together to share success stories and discuss ways to tackle childhood obesity. Let's Move also uses its Facebook page as a connector for communities to share tips and news from across the country.
http://www.letsmove.gov/

- **Practical Playbook:** This resource for public health and primary care groups features an interactive tool that guides users through the stages of integration for population health improvement projects. Information on how to scale up efforts is included.
http://www.practicalplaybook.org/

Element 10: Resources for a Plan for Sustainability

- **Healthier Worksite Initiative**: This resource from the CDC addresses workforce health promotion and offers information, resources, and step-by-step toolkits to help worksite health promotion planners in the public and private sectors improve the health of employees. http://www.cdc.gov/nccdphp/dnpao/hwi/

- **A Sustainability Planning Guide for Healthy Communities:** The CDC's Healthy Communities Program has worked with more than 300 community coalitions to help create a culture of healthy living while building national networks for sustainable change. The Sustainability Planning Guide provides evidence-based insights to help coalitions, public health professionals, and other community stakeholders develop, implement, and evaluate a successful sustainability plan. http://www.cdc.gov/nccdphp/dch/programs/healthycommunitiesprogram/pdf/sustainability_guide.pdf

Appendix C: Example Lists of Measures

Notes

- The goal by the end of this project (Option Year two) is to have a recommended menu of measures to choose from, listed in the final Guide. Field Test Groups will help identify the most useful measures.

Questions

1. Which approach to measures should be used in the final Guide:
    a. List a small set of individual measures that are recommended for use by everyone (and if so, what should those measures be?)
    b. List an array of measures from which to select (and if so, what guidelines or parameters should be used to identify which measures should be on that list?)
    c. Some other approach (please describe)
2. For the final Guide, what information should be included with each measure? (e.g., determinant of health, level of analysis, link to measure details, pre-calculated results using a standard data source, ideas for data sources so you can calculate your own results)
3. Which measure sources (listed below or not) are you using and how are you using them?
    a. Of the measures you use now (e.g., as currently structured, described, available, etc.), which are easier to use and why? Which are more difficult and why?
4. What other measures (or measure lists) would you like to use and for what purpose?
    a. What changes would make the measures more useful or easier to use (e.g., level of detail, availability of a data source or pre-calculated results, frequency of updates)?

Lists of Measures that Might be Included in the Final Version of the Guide

Healthy People 2020 – Measure Domains
This national project defines four areas of health measures used to monitor progress toward promoting health, preventing disease and disability, eliminating disparities, and improving quality of life. These broad, cross-cutting areas of measurement include general health status; health-related quality of life and well-being; determinants of health; and disparities.
http://www.healthypeople.gov/2020/about/tracking.aspx

Healthy People 2020 – Leading Indicators of Health
Representing a smaller set of objectives for high-priority health issues, the 26 Leading Health Indicators have baseline and target levels specified, as well as data sources included for each.
http://www.healthypeople.gov/2020/LHI/2020indicators.aspx

County Health Rankings and Roadmaps

The County Health Rankings score communities according to a variety of health measures based on health outcomes and health factors, which are broken down into eight composite areas and then into subcomponent areas.
http://www.countyhealthrankings.org/sites/default/files/resources/2013Measures_datasources_years.pdf

A Healthier America 2013: Strategies to Move from Sick Care to Health Care in Four Years

This strategic paper suggests Public Health Accreditation Board (PHAB) accreditation standards in 12 domains: 10 essential public health services; management and administration; and governance. See page 10 of the report.
http://healthyamericans.org/report/104/

Clinical-Community Relationships Measures Atlas

This measurement framework lists existing measures for clinical-community relationships and explores ways to define, measure, and evaluate programs that are based on such relationships for the delivery of clinical preventive services. The list of existing measures includes detailed information on the measure's purpose, format, and data source, validation and testing, applications, and key sources. The Master Measure Mapping Table provides an overview of domains and the relationships involved. See page 10 of the report.
http://www.ahrq.gov/professionals/prevention-chronic-care/resources/clinical-community-relationships-measures-atlas

Early Education Readiness Using a Results-Based Accountability Framework

A collaborative of parents and child-serving organizations in Los Angeles County worked together to establish a set of school readiness indicators. The workgroup used the National Education Goals Panel's (NEGP's) working definition of school readiness: children's readiness for school, school's readiness for children, family and community supports, and services that contribute to children's readiness for school success. Indicators were also chosen to reflect the five outcomes adopted by Los Angeles County: good health; safety and survival; economic well-being; social and emotional well-being; and education/workforce readiness.
http://www.first5la.org/files/ShapingtheFutureReport.pdf

Guide to Measuring the Triple Aim: Population Health, Experience of Care, and Per Capita Cost

This 2013 white paper from the Institute for Healthcare Improvement suggests measures for the three dimensions of the Triple Aim, accompanied by data sources and examples, with descriptions of how the measures might be used.
http://www.ihi.org/resources/Pages/Measures/default.aspx

Healthy Communities Data and Indicators Project (HCI)

To serve a goal of enhancing public health, this project includes the development of a standardized set of statistical measures for use in community health planning and assessment. A draft core list of indicators was developed in 2013 and more than 50 indicators are being vetted and constructed, with information on the impact, evidence, data sources, bibliographic references, and methods and limitations of each.

http://www.cdph.ca.gov/programs/Pages/HealthyCommunityIndicators.aspx

http://www.cdph.ca.gov/programs/Documents/Healthy_Community_Indicators_Core_list1-15-13Table1-5.pdf

HHS Action Plan to Reduce Racial and Ethnic Disparities

The action plan is based on national goals and objectives for addressing health disparities identified by Healthy People 2020 and focuses on evidence-based programs and best practices. Stakeholders include HHS public and private partners, plus other federal partners working together on the initiative, including the Departments of Agriculture (USDA), Commerce (DOC), Education (ED), Housing and Urban Development (HUD), Labor (DOL), Transportation (DOT), and the Environmental Protection Agency (EPA). See Appendix C, page 44 for measures.

http://minorityhealth.hhs.gov/npa/templates/content.aspx?lvl=1&lvlid=33&ID=285

Regional Equity Atlas 2.0 and Action Agenda

This population health improvement tool maps the intersection of chronic disease prevalence data and data on the social, economic, and physical determinants of health for the Portland metro region, providing insight into key findings. The tool covers a set of domains that includes measures spanning clinical care, demographics, environment, and social characteristics.

https://clfuture.org/programs/regional-equity-atlas/maps-and-analysis

Toward Quality Measures for Population Health and Leading Health Indicators

Measurement domains include 26 leading health indicators outlined in Healthy People 2020 as well as 12 additional topics: access to health services; clinical preventive services; environmental quality; injury and violence; maternal, infant, and child health; mental health; nutrition, physical activity, and obesity; oral health; reproductive and sexual health; social determinants; substance abuse; and tobacco. See page 15 of the report.

http://www.iom.edu/Reports/2013/Toward-Quality-Measures-for-Population-Health-and-the-Leading-Health-Indicators.aspx

Appendix D: Example Lists of Data Sources

Notes:

- The goal by the end of this project (Option Year two) is to get input on key data sources (credibility of methodology, desired uses and whether the age / recency of the data is an issue, understandability). Field Test Groups will help identify the most useful data sources.

Questions

1. Which data sources are useful and easy to use, just as they are now (i.e., as *currently* structured, described, available, etc.)?

2. Which data sources *could be useful or easier to use* if they were changed in some way (e.g., structure, description, availability, frequency of updates)?

3. Which data sources (listed below or not) are you using and how are you using them?

4. What other types of data sources would you like to access and use, and for what purpose?

Data Sources Under Consideration for Inclusion in the Final Version of the Guide

Center for Vital Statistics Health Data Interactive
This resource presents tables with national health statistics for infants, children, adolescents, adults, and older adults. Tables can be customized by age, gender, race/ethnicity, and geographic location to explore different trends and patterns.
http://www.cdc.gov/nchs/hdi.htm#tutorials

Behavioral Risk Factor Surveillance System (BRFSS)
BRFSS is an on-going telephone health survey system focused on collecting behavioral health risk data. The annual survey data is published online and used by the Centers for Disease Control and Prevention (CDC) and other federal agencies.
http://www.cdc.gov/brfss/about/index.htm

Correctional Health Outcomes and Records Data Set (CHORDS)
CHORDS is a clinical outcomes data sharing system being designed for correctional healthcare settings. Data is supplied by jails and other correctional facilities.
http://www.ncchc.org/chords

County Health Rankings and Roadmaps
The County Health Rankings score communities according to a variety of health measures based on health outcomes and health factors, which are broken down into eight composite areas and then into subcomponent areas.
http://www.countyhealthrankings.org/app/home

Data.Gov

The U.S. government's data portal provides access to federal, state and local data, as well as tools, research resources and more. The "Health" section includes 1,125 data sets, tools and applications related to health and healthcare and can be used as a resource for groups or individuals looking for examples of data or actual data sets for reporting purposes.
https://www.data.gov/health/

Data.CDC.Gov

This online database provides access to data sources from the Centers for Disease Control and Prevention (CDC).
https://data.cdc.gov/

Gallup-Healthways Well-Being Index

The Gallup-Healthways Well-Being Index is a measure derived from an empiric database of real-time changes in factors that drive well-being. The database captures perceptions on topics such as physical and emotional health, healthy behaviors, work environment, social and community factors, financial security, and access to necessities such as food, shelter and healthcare. Gallup conducts 500 telephone interviews a day with Americans to gather their perceptions of well-being, for a resulting sample that represents an estimated 95 percent of all U.S. households.
http://www.healthways.com/solution/default.aspx?id=1125

National Institutes of Health (NIH) Data Sharing Repository

The National Library of Medicine (NLM) website provides a table of NIH-supported data repositories that accept submissions of appropriate data from NIH-funded investigators (and others). Also included are resources that aggregate information about biomedical data and information sharing systems.
http://www.nlm.nih.gov/NIHbmic/nih_data_sharing_repositories.html

Appendix E: Example Lists of Tools

Notes

- By end of this project (Option Year Two), the Action Guide may be an online resource. Field Test Groups will help identify the most useful tools.

Questions

1. Which resources or tools are useful and easy to use, just as they are now (e.g., as currently structured, described, available, etc.)?

2. Which resources or tools could be useful or easier to use if they were changed in some way (e.g., structure, description, availability, frequency of updates)?

3. Which resources or tools (listed below or not) are you using and how are you using them?

4. What other types of resources or tools would you like to access and use, and for what purpose?

Resources or Tools Under Consideration for Inclusion in the Final Version of the Guide

ACHI Community Health Assessment Toolkit
The ACHI Community Health Assessment Toolkit is a guide for planning, leading, and using community health needs assessments to better understand and improve the health of communities. Tools include checklists, budgets, and timeline guides and templates for each of the six steps in the framework, with specific guidance on skills needed, budget drivers, time drivers, and a task checklist.
http://www.assesstoolkit.org/

The Blue Zones Project
The Blue Zones Project focuses on encouraging individuals and community members to aspire to healthy lifestyle ideals, which are based on research into communities around the world with the highest number of centenarians. An online community provides guidance and tips ranging from healthy eating to stress management, and the project also includes “policy pledge actions” for schools, workplaces, local government entities and communities pertaining to the physical environment, food, and smoking.
https://www.bluezonesproject.com/

Camden Care Management Program and Cross-Site Learning
This program through the Camden Coalition of Healthcare Providers includes development of a database to analyze and quantify the utilization of hospitals by Camden, New Jersey residents. This tool relies on data from the Camden’s Health Information Exchange (HIE) to target and coordinate care for patients who lack consistent primary care and often suffer from chronic illness, mental illness, and substance abuse. The Cross Site Learning program is being implemented in 10 cities. Tools, planning guides, and other materials are being provided to expand "hot spotting" to other locations.
http://www.camdenhealth.org/cross-site-learning/

County Health Rankings and Roadmaps

The Roadmaps to Health Action Center provides an interactive framework ("The Action Cycle") for organizing and planning initiatives, projects and collaborative actions aimed at population health improvement. The County Health Rankings is a tool providing information about the health of populations by county, including health outcomes and a broad set of health determinants. The website provides access to all of the data underlying the rankings and a guide to evidence-based policies, programs and system changes ("What Works for Health") and a "Tools & Resources" page with external links to educational materials and additional tools.
http://www.countyhealthrankings.org/

Family Wellness Warriors Initiative

This Alaska-based antidomestic violence initiative holds multiday trainings to educate "natural helpers" and community members on how to work with people affected by violence, reduce abuse in the community, and implement the program's antiviolence curriculum. The program's website also includes a map with localized resources, such as counseling centers, for violence and abuse prevention.
http://www.fwwi.org/index.cfm

Green Strides

This is a U.S. Department of Education initiative aimed at making all schools healthier, safer, and more sustainable. Resources include a webinar series, blog, and social networking to facilitate sharing of best practices and resources. The resources page lists tools for schools, teachers, parents, and students to use in planning and execution of improvement strategies, such as reducing environmental impact and cost, promoting health and wellness, and learning about environmental sustainability.
http://www2.ed.gov/about/inits/ed/green-strides/resources.html#topic2

The Guide to Community Preventive Services

The Guide to Community Preventive Services is a free resource to help identify programs and policies to improve health and prevent disease in the community, based on recommendations from the Community Preventive Services Task Force.

http://www.thecommunityguide.org/index.html

Healthy Communities Institute (HCI)

The Healthy Communities Institute provides customizable, web-based information systems to visualize the best-available local data through indicator dashboards and GIS maps. Supporting tools include Indicator Trackers for evaluation, a database of more than 2000 best practices, and collaboration tools to support ongoing collective work. The database includes more than 100 quality of life indicators for any community and the ability to add custom indicators locally. The Healthy People 2020 Tracker helps evaluate the effectiveness of the local group's programs and the health of the community compared to national goals, and custom trackers can be locally created to track local priorities and progress towards locally defined targets.

http://www.healthycommunitiesinstitute.com/

Health in All Policies: A Guide for State and Local Governments
The Health in All Policies guide includes "Food for Thought" questions in each section that leaders of a Health in All Policies initiative are encouraged to consider. The guide also includes tips for identifying new partners, building meaningful collaborative relationships across sectors, and maintaining those partnerships over time, as well as more than 50 annotated resources for additional support.
http://www.phi.org/resources/?resource=hiapguide

Let's Move
Online resources from the Let's Move initiative include "5 simple steps" guides for parents, schools, community leaders, chefs, children, elected officials and healthcare providers on how to play a role in preventing and reducing childhood obesity and living and promoting healthier lifestyles. The website also includes educational materials for printing and distribution within communities.
http://www.letsmove.gov/action

Moving Healthy
This overview of the health-related strategies being explored by the U.S. Department of Transportation Federal Highway Administration (FHWA) references tools and resources to help transportation professionals and health practitioners identify and address the health impacts of transportation.
https://www.fhwa.dot.gov/planning/health_in_transportation/resources/moving_healthy.cfm

The National Prevention Strategy
The Surgeon General's website for this national initiative features resources related to the National Prevention Strategy, including fact sheets, infographics, implementation, and scientific resources.
http://www.surgeongeneral.gov/initiatives/prevention/resources/index.html

The National Service Frameworks
This is a collection of strategies from the National Health Service (NHS) in the United Kingdom to address the prevention and treatment of cancer, coronary heart disease, COPD, diabetes, kidney care, long-term conditions, mental health issues, and stroke, as well as caring for the elderly and providing end of life care. The webpages for each framework include educational materials and links to additional resources, such as nonprofit organizations and further information within the NHS.
http://www.nhs.uk/nhsengland/NSF/pages/Nationalserviceframeworks.aspx

One in 21 Muskegon County
This is the umbrella program for local initiatives like "Project Healthy Grad" and includes educational information, links to farmers' markets and other local resources for Muskegon County, Michigan.
http://1in21.org/resources

Operation Live Well
This initiative aimed at improving the health of military personnel and their families includes resources related to key focus areas and preventive health, plus a list of health tools from various organizations.
http://www.health.mil/livewell

Practical Playbook
This resource for public health and primary care groups features an interactive tool that guides users through the stages of integration for population health improvement projects.
http://www.practicalplaybook.org/

Regional Equity Atlas 2.0 and Action Agenda
This project includes maps the Portland, Oregon region using data on chronic disease prevalence and social, economic, and physical determinants of health, and provides key findings. A mapping tool allows for customized creation of maps on issues affecting the region.
https://clfuture.org/equity-atlas

Shaping the Future Report
This report presents school readiness goals and indicators to guide planning and accountability around children's readiness for school in Los Angeles County. The tool was created to engage community stakeholders, monitor trends, and implement a results-based accountability framework.
http://www.first5la.org/research/shaping-the-future-report

The Substance Abuse and Mental Health Services Administration (SAMHSA)
SAMHSA provides resources and guidance on substance abuse, mental illness, trauma and justice, health reform, health information technology, public awareness and support, outcomes and quality, and recovery support. This includes access to tools, materials, and links to external organizations.
http://www.samhsa.gov/

Vermont Blueprint for Health
This is a state-led initiative aimed at transforming the way that healthcare and health services are delivered in Vermont by providing the community with a continuum of seamless, effective, and preventive health services, while reducing medical costs. Tools include healthier living and tobacco cessation workshops, plus educational materials and guidance on how to implement the Blueprint.
http://hcr.vermont.gov/blueprint

YMCA Healthier Communities Initiatives
The YMCA provides resources for promoting healthier communities, including a guide on linking policy and environmental strategies to health outcomes and the Community Health Living Index (CHLI), which contains self-assessments and provides best practices to promote improvement.
http://www.ymca.net/healthier-communities

Appendix F: Population Health Framework Committee Roster

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Addressing Performance Measure Gaps in Home and Community-Based Services to Support Community Living:

Synthesis of Evidence and Environmental Scan

INTERIM REPORT

DECEMBER 18, 2015

NATIONAL
QUALITY FORUM

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CONTENTS

EXECUTIVE SUMMARY

The Addressing Performance Measure Gaps in Home and Community-Based Services to Support Community Living Project aims to develop a shared understanding and approach to assessing the quality of home and community-based services (HCBS) and to identify gaps in current HCBS quality measurement as well as high-leverage opportunities for measure development. Understanding the quality of HCBS becomes increasingly important as government funding shifts from institutional to community-based settings, and demand for HCBS rises. A growing number of programs offer services and support to help individuals live independently in integrated community settings. However, despite this growth, there is a lack of systematic measurement of the quality of HCBS across payers and delivery systems.

To address this issue, the National Quality Forum (NQF), under a contract with the Department of Health and Human Service (HHS), convened a **multistakeholder Committee** to develop recommendations for the prioritization of measurement opportunities to address gaps in HCBS quality measurement. The two-year project involves:

1. the creation of a conceptual framework for measurement, including an operational definition of HCBS;
2. a synthesis of evidence and environmental scan for measures and measure concepts;
3. the identification of gaps in quality measurement based on the framework and scan; and
4. recommendations for prioritization in measurement.

The first interim report, **Addressing Performance Measure Gaps in Home and Community-Based Services to Support Community Living: Initial Components of the Conceptual Framework**, presented the Committee's foundational work of creating an operational definition, characteristics of high quality HCBS, domains of measurement as well as an illustration of the function of performance measurement in HCBS. This report, building on the first report and related efforts, focuses on the findings of the synthesis of evidence and environmental scan for measures.

The purpose of the synthesis of evidence and environmental scan is to assess the current HCBS quality measurement landscape. The findings will be used to inform the Committee's efforts to prioritize measure gaps and identify opportunities for measure development. NQF conducted a multi-step approach to the synthesis of evidence and environmental scan which included the collection and review of information sources as well as a review of example state-level (Minnesota, Oregon, and Washington) and international (England, Canada, and Australia) quality measurement initiatives.

Under the guidance of the Steering Committee, the Department of Health and Human Services Advisory Group, NQF members, and the public, over 270 information sources were identified. An annotated bibliography contains these sources, which were obtained from research publications, grey literature, measure repositories, and previous environmental scans. NQF extracted measures, measure concepts, and instruments from these sources that assess the quality of HCBS and closely match the domains of measurement identified by the Committee. For the purposes of this work, NQF defined measures, measure concepts, and instruments as follows:

- A measure is a metric that has a specific numerator and denominator and has undergone scientific testing.
- A measure concept is a metric that has a specific numerator and denominator, but has *not* undergone testing.
- An instrument is a psychometrically tested and validated survey, scale, or other measurement tool.

NQF identified 261 measures, 394 measure concepts, and 75 instruments, which are displayed in the **compendium of measures**. The majority of measures, measure concepts, and instruments were found in the domains of Service Delivery, System Performance, Effectiveness/Quality of Services, Choice and Control, and Health and Well-Being. No or fewer measures, measure concepts, or instruments were found in the domains of Consumer Voice, Equity, Community Inclusion, and Caregiver Support.

NQF also reviewed state-level and international quality measurement activities in three states and three countries. These example initiatives were reviewed to illustrate the types of efforts happening within the U.S. and abroad. For instance, Washington State is currently developing two measures sets to assess a variety of consumer outcomes like improved health status and improved satisfaction with quality of life. Oregon and Minnesota are currently piloting and utilizing new instruments to better evaluate HCBS consumer experience. Similarly, governing bodies within England, Canada, and Australia have begun developing and implementing standard measure sets and frameworks to assess the quality of their HCBS systems.

During the next steps of the project, the Committee will discuss the findings of the synthesis of evidence and environmental scan. They will also consider the feasibility of measurement, barriers to implementation, and mitigation strategies for identified barriers. As this is an iterative process, there will be several opportunities for the Committee, NQF members, and the public to provide feedback throughout the project as it will continue through September 2016.

BACKGROUND AND CONTEXT

Environmental Context

The United States is experiencing a major shift in the nation's demographics with a rapid increase in the number of people who require long-term services and supports (LTSS). LTSS are generally considered to include assistance with activities of daily living (ADLs) and instrumental activities of daily living (IADLs) for older adults and/or people with disabilities who cannot perform these activities on their own due to a physical, cognitive, or health condition. The category of LTSS is broad and includes care and service coordination for people who live in their own home, a residential setting, a nursing facility, or other institutional setting. Home and Community-Based Services (HCBS) is a subset of LTSS that functions outside of institutional care to maximize independence in the community. Both LTSS and HCBS also include supports provided to family members and other unpaid caregivers of individuals with LTSS needs.

Demand for these services is increasing and will continue to do so. The Administration for Community Living (ACL) reports that the number of people 65 years of age and older will exceed 70 million by 2030, accounting for 19 percent of the population and doubling the total number of older Americans since 2000.[1] In 2013, 37 million people in the U.S. were classified as having a disability, with more than 50 percent of that total in their working years (18-64).[2] In addition, approximately 60 million Americans experience a mental illness annually, and 13.6 million people are currently living with chronic mental illness.[3] Finally, projections show that 21 million individuals are expected to be living with multiple chronic conditions by 2040, many of whom will require LTSS.[4] An increasing share of LTSS is comprised of HCBS, promoting independence and wellness outside of institutional settings.

HCBS accounted for a majority of Medicaid long-term services and supports (LTSS) expenditures for the first time in federal fiscal year (FY) 2013. Total federal and state LTSS spending was $146 billion, including $75 billion for HCBS and $71 billion for institutional LTSS. These expenditures are expected to grow dramatically in concert with demand.[5] Given the anticipated growth in Medicaid coverage and the breadth of services covered through HCBS, this is a critical time to better understand performance of these services and their contribution to the HHS goals of building a health system that delivers better care, spends healthcare dollars more wisely, and makes communities healthier. Through the federal-state partnership of Medicaid, the Centers for Medicare & Medicaid Services (CMS) and states are the dominant funders of HCBS. As a result, CMS and states also drive much of the current quality monitoring and quality measurement activity in the marketplace.

However, HCBS extends well beyond services purchased by Medicaid. First, a host of other federal, state, and local programs provide HCBS. These include ACL, the Substance Abuse and Mental Health Services Administration (SAMHSA), the Administration for Children and Families (ACF), the Health Resources and Services Administration (HRSA), and others. In addition, there is a large and growing private-pay market for HCBS. Finally, HCBS consumers receive assistance from family members, friends, and volunteers in the form of informal care, in addition to paid or formal services. As a quality measurement framework for HCBS continues to emerge, a number of issues must be considered. These include the relationships between various funding streams, regulators, the extensive and diverse network of HCBS providers, service delivery models including self-direction, and the potential implications for how measurement systems will align across the evolving health and LTSS systems.

PROJECT OVERVIEW

Over the past decade, the National Quality Forum (NQF) has endorsed hundreds of performance measures to address important areas for improving health and healthcare. At the same time, many measure gaps have been identified, but the lack of an organizing framework through which to analyze and prioritize them has presented a challenge in determining where scarce resources should be allocated for future development. With the development of the HHS National Quality Strategy for Improvement in Health Care (National Quality Strategy or NQS), a clear blueprint is now in place to better assess critical gaps in quality and efficiency measures.[6] One important gap is the lack of measures that address HCBS that support community living. NQF's completed and current measure gap prioritization projects lay a foundation for setting goals and coordinating action in measure development in high-impact areas. The significance of quality measurement in HCBS is heightened as more care is being delivered in community settings.

The purpose of this project is to further advance the aims and priorities of the Affordable Care Act (ACA), the NQS, and the previous work of HHS' Community Living Council by identifying priorities for performance measurement, scanning for potential measure concepts to address these priorities, and developing multistakeholder recommendations for future measure development and advancement. This project utilizes a comprehensive approach to considering all types of people who could, and do, use HCBS. It includes both government and private sector funding sources for HCBS. This report, the second of four to be produced over the life of the project, builds on the first interim report that presented the conceptual framework and operational definition drafted by the Home and Community-Based Services Quality Measurement Committee. The Committee roster is provided in Appendix A.

The recommendations generated through this project will be instrumental in identifying high-impact areas for future HCBS measurement and influential on the process of developing a nationally endorsed and accepted quality measure set for HCBS. The two-year NQF project involves:

1. the creation of a conceptual framework for measurement, including an operational definition of HCBS;
2. a synthesis of evidence and environmental scan for measures and measure concepts;
3. the identification of gaps in quality measurement based on the framework and scan; and
4. recommendations for prioritization in measurement.

This project is intended to build upon previous and/or ongoing work related to HCBS quality in order to provide a unified picture of HCBS quality measurement and to identify opportunities for measure development. Its intent is to provide a framework through which stakeholders can align broader measure development efforts by ensuring that financial and human resources are purposefully targeted. The work will quicken the pace of development and use of national measures of HCBS that matter to consumers, families, and stakeholders at all levels of the system who have a role in improving HCBS quality.

Initial Components of the Conceptual Framework

In the first interim report, the Committee crafted an operational definition for HCBS to reach a common understanding of what it does and does not include. Following the creation of the definition, the Committee identified characteristics of high-quality HCBS that outline how services should be delivered. The Committee's list of characteristics is extensive but important for framing the vision for quality. These characteristics express the importance of ensuring the adequacy of the HCBS workforce, integrating healthcare and social services, supporting the caregivers of individuals who use HCBS, and fostering a system that is ethical, accountable, and centered on the achievement of an individual's desired outcomes.

The Committee delineated a universe of domains and subdomains for quality measurement as the first step towards later prioritization. The Committee identified a total of 11 quality measurement domains which point to important areas for measurement and/or measure development. Numerous potential subdomains for measurement exist under each of the domains, and the Committee has begun the process of defining them. Finally, these components of the conceptual framework and other aspects of the Committee's discussion are represented in an illustration of the function of quality measurement. The most recent iteration of the operational definition, characteristics of high-quality HCBS, and domains appear in **Appendix D**. The Committee will continue to refine these components throughout the project.

Related Efforts in HCBS and Measurement

There have been several ongoing and related efforts, at the federal policy level and in the realm of quality measurement, to support improvement in HCBS. For example, the Deficit Reduction Act (DRA) of 2005 (PL 109-171, Section 6086(b)) directed the Agency for Healthcare Research and Quality (AHRQ) to develop HCBS quality measures for the Medicaid program. To lay the groundwork for meeting these requirements, AHRQ contracted with Thomson Reuters (now Truven Health Analytics) to conduct an environmental scan of existing and potential measures.[7] While the scan is now several years old, it was thorough and included more than 200 measure sources. NQF is updating and building upon this work and other previously completed efforts to identify measures, potential measure concepts, and instruments for HCBS.

CMS has sponsored the development of an HCBS taxonomy further explaining the types and uses of HCBS. Under Medicaid, a wide array of services and supports has been approved as HCBS including personal care, homemaker, habilitation, transportation, case management, supported employment, environmental modifications, respite care, and support broker and financial management services that may be required in self-directed service delivery models.[8] This taxonomy is to be implemented into the new version of the Medicaid Statistical Information System (MSIS), which gathers national eligibility, enrollment, program utilization, and expenditure data.

In addition, CMS awarded Testing Experience and Functional Tools (TEFT) planning grants to nine states to test quality measurement tools and demonstrate e-health in Medicaid community-based long-term services and supports (CB-LTSS).[9] The TEFT initiative is currently working on a HCBS consumer experience of care survey, functional assessment of standardized items (FASI), and development of standards for an electronic long-term services and supports (eLTSS) health record and a personal health record.[9] Progress is currently being fostered through Medicaid, and there is potential to expand and share the results.

These are examples of the dozens of important inputs to the Committee's work. Despite the existence of several established frameworks and/or lists of quality measurement domains for LTSS and HCBS, the availability and uptake of performance measures remain limited and lack uniformity across states and across other levels of analysis (e.g., provider, managed care organization). In light of the increasing use of HCBS nationally and the associated costs, this is a deficit in quality measurement. Stakeholders have called for more systematic measurement for many years, but the current environment reflects the fragmented nature of the decentralized HCBS system as well as a historical lack of consensus about the best path forward for implementation of measurement. NQF will continue to research previous and current efforts to advance this project.

PURPOSE AND OBJECTIVES

This report details the synthesis of evidence and environmental scan for measures, measure concepts, and instruments that assess the quality of HCBS. The purpose of the synthesis of evidence and environmental scan is to inform the Committee's task to identify measure gaps and promising opportunities for measurement by providing an overview of the current HCBS quality measurement landscape. The approach to the synthesis and scan was carefully developed by NQF staff, with input from the Steering Committee and Department of Health and Human Services Advisory Group (**Appendix A**) crafted to capture the wide range of HCBS populations, services, and settings that align to the domains and subdomains developed by the Committee. The objectives of the synthesis of evidence and the environmental scan are to:

- identify existing measures, measure concepts, and instruments that are being used or proposed conceptualized for use to assess HCBS quality, with an emphasis on those that map to the draft conceptual framework's domains and subdomains;
- identify examples of HCBS measures to guide the Committee's discussion of implementation barriers and mitigation strategies, that is, a selection of measures that lend themselves to examination as "test cases"; and
- facilitate the Committee's deliberations on the identification of key measurement gaps and prioritization of measure concepts and instruments that should be developed into future HCBS performance measures.

The measures that were found are not exhaustive but provide a detailed overview of the current state of measurement. The Committee will review and interpret the findings of the environmental scan during the next phase of the project. Throughout this project, NQF will continue to be guided by related efforts (e.g., the CMS planning grants (i.e., TEFT) and build on previously completed work such as the Prioritizing Measure Gaps projects on Alzheimer's Disease and Related Dementias, Care Coordination, and Person-Centered Care and Outcomes. As this is an iterative process, there will be several opportunities for the Committee, NQF members, and the public to further refine and make additions to the findings of the environmental scan as this work continues.

METHODOLOGY

Approach

NQF conducted a three-step approach to the synthesis of evidence and environmental scan which included: (1) a collection of information sources; (2) the review of information sources (i.e., extraction of measure, measure concepts, and instruments); (3) and a review of state-level (Minnesota, Oregon, and Washington) and international (England, Canada, and Australia) HCBS systems to highlight burgeoning quality measurement initiatives. For the purpose of this project, NQF defined measures, measure concepts, and instruments:

- A measure is a metric that has a specific numerator and denominator and has undergone scientific testing for reliability and validity.
- A measure concept is a metric that has a specific numerator and denominator, but has not undergone scientific testing.
- An instrument is a psychometrically tested and validated survey, scale, or other measurement tool.

Although the term "measure" is often used to refer to multi-item instruments used to obtain data from individuals about a particular domain of health status, quality of life, or experience with care (e.g., Patient Health Questionnaire-9 [PHQ-9]), such instruments alone do not constitute a performance measure. However, if considered a reflection of performance, aggregated data from such instruments can be used as the basis of a performance measure, with additional scientific testing. Psychometrically tested and validated instruments directly relevant to HCBS were collected in the scan, but NQF staff did not extract individual items from the instruments found. However, in some cases, measures or measure concepts items already in use from an instrument (e.g., Consumer Assessment of Healthcare Providers and Systems (CAHPS®) Survey measures) were identified and included.

Collection of Information Sources

NQF conducted a search for information sources relevant to HCBS that met the inclusion and exclusion criteria outlined in Appendix B. During this search, NQF examined the grey literature (e.g., technical reports, preliminary progress reports, and white papers), peer-reviewed research publications, measure repositories, and relevant environmental scans. Previous NQF reports and environmental scans were included in the grey literature search. Databases for the literature review included Academic Search Premier, PubMed/Medline, Google Scholar, PsychINFO, PAIS International, Ageline, Cochrane Collaboration, and Campbell Collaboration. NQF conducted a targeted search within these databases using various combinations of keywords that were derived from the domains and subdomains of the Committee's conceptual framework. The keywords used in this search can be found in Appendix C. The Steering Committee, the HHS Advisory Group (AG), and several HCBS stakeholder groups assisted in identifying additional information sources. Over 270 information sources were identified and reviewed. Many of these sources were used to inform the development of the components of the conceptual framework detailed in the first interim report. These sources were also used to identify measures, measure concepts, and instruments for the environmental scan. These sources can be found in the Annotated Bibliography.

Review of Information Sources

Sources were ranked according to their relevance and were assigned impact ratings based on three evaluation criteria (i.e., impact, improvability, and inclusiveness) from the Institute of Medicine's *Priority Areas for National Action: Transforming*

Health Care Quality report. These ratings are outlined in Appendix B. Measures, measure concepts, and instruments were extracted from the information sources that were rated highly and were evaluated based on criteria developed from the 2010 AHRQ Environmental Scan of Measures for Medicaid Title XIX Home and Community-Based Services. These criteria can be found in Appendix B. Each measure was rated according to the information that was available within the source from which it was extracted.[a]

Many measures and instruments contained in the literature have been captured in web-based measure repositories. NQF searched measure repositories and extracted measures by applying the inclusion and exclusion criteria outlined in Appendix B. Some of these repositories include the HHS Measures Inventory, the AHRQ National Quality Measures Clearinghouse, CMIT Inventory, Health Indicators Warehouse, HCBS Clearinghouse, and the National Inventory of Mental Health Quality Measures. NQF also reviewed its internal measure repository which includes all measures that have ever been submitted to NQF for endorsement (i.e., endorsed and not endorsed). The complete list of measures, measure concepts, and instruments are displayed in the Compendium of Measures.

Review of Federal Programs Materials

NQF reviewed materials pertaining to federal agency programs involved with the delivery of, or payment for, HCBS. This process began by identifying and compiling a list of these programs through a review of the information sources from the annotated bibliography as well as team discussions. These included programs funded by CMS (e.g., section 1915(c)Medicaid HCBS waivers and State Plan Amendments; the Program for All-Inclusive Care of the Elderly Program), the Administration for Community Living (e.g., Older Americans Act programs), the Substance Abuse and Mental Health Services Administration (e.g., suicide prevention programs, mental health block grants), the Department of Housing and Urban Development (e.g., Housing for Persons with Disabilities), the U.S. Department of Agriculture (e.g., Senior Farmers' Market Nutrition Program), and the Veterans Health Administration (e.g., the Home Base Primary Care program). For each non-Medicaid program, NQF staff reviewed information sources related to the program, reviewed program websites, and contacted program staff in the three selected states to inquire about the use of measures or instruments.

Given the large role Medicaid plays in the delivery of HCBS, a more detailed description of the review strategy for Medicaid programs is provided below. Review of Medicaid programs began with the section 1915(c) HCBS Waivers. The program was examined by reviewing a repository of state section 1915(c) performance measures at a point in time provided to NQF by the HHS AG. The AG also furnished a list of services CMS has approved as HCBS. This repository contained the performance measures (n=10,709) included in the 1915(c) applications from 46 states and the District of Columbia. The review of this document included:

1. removal of 2,461 performance measures that did not specify a numerator or denominator
    a. This step was completed by searching the performance measure descriptions for the words "numerator," "number," or "percentage" or the symbols "#" or "%".
2. removal of 1,634 performance measures from waivers with waiver expiration dates prior to 2015[b]
3. categorization and review of the remaining 6,614 performance measures across assurance categories[c]

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[a] If testing information was not available in the source from which the measure was extracted, the measure would be attributed to evidence level B or level I, and classified as a measure concept.

[b] Performance measures for 1915(c) waiver programs on temporary extensions may not be represented in this sample set.

[c] Assurances are those areas for which each state must propose performance measures for the purposes of monitoring and assuring the quality of services offered within the waiver program. The assurance categories are Administrative Authority, Level of Care, Qualified Providers, Service Plan, and Financial Authority.

Upon review of these categories, it was determined that many states utilized similar measures across assurance categories. Performance measures from Minnesota, Oregon, and Washington waiver programs were chosen to serve a sample set of section 1915(c) waiver performance measures. These states were considered ideal for in-depth analysis as their HCBS spending as a percentage of LTSS spending is among the highest in the country. To ensure that all section 1915(c) waiver performance measures from these three states were included in the sample set, NQF staff crossed-checked the waivers included in the measure repository provided by the HHS AG with the section 1915(c) waiver applications available for each selected state on the CMS Medicaid Demonstrations and Waivers website. Through this cross-check, additional 1915(c) waiver applications were identified and reviewed for performance measures. Any identified performance measures, measure concepts, or instruments were extracted and added to the compendium. For the section 1915(b) waivers, section 1915(i), State Plan Amendments, section 1915(j), and 1115 Medicaid demonstration waiver programs, documentation (i.e., applications, submitted State Plan Amendments) for Minnesota, Oregon, and Washington were retrieved from the CMS Medicaid Demonstrations and Waivers website and reviewed. NQF reviewed available documentation for the section 1915(k) Community First Option State Plan Amendments, for all participating states, specifically Oregon, Washington, California, Montana, and Texas. For the Balancing Incentive Program, documentation available from The Technical Assistance Center for the Balancing Incentive Program was reviewed. This Center provides a summary of services, quality, and outcomes data collected by the 20 participating states.. Measures or instruments listed in this summary were retrieved, if possible, and reviewed. For CMS's "rebalancing" demonstration program, Money Follows the Person, the evaluation and report documents available on the Money Follows the Person Medicaid websites were reviewed. Any measures, measure concepts, or instruments identified in the review of these programs were extracted and added to the compendium of measures. The National Balancing Indicators Project provided information to refine eighteen common core indicators and short-term developmental indicators. This work, which supported state system rebalancing efforts, was also reviewed.

Review of Selected State and International Quality Measurement Activities

NQF interviewed state officials from Washington, Oregon, and Minnesota and reached out to individuals who work in the HCBS systems of England, Canada, and Australia to identify current and emerging HCBS quality measurement initiatives. The states and countries were selected to illustrate performance measurement in high-performing systems. Representatives provided information on seminal works, relevant legislation, and quality measurement frameworks as well as the overall structure of how HCBS is delivered (i.e., funding, key organizations, and governance). NQF also conducted a high-level literature review to identify information sources (e.g., peer-reviewed literature, white papers, and government reports) that provided additional context and insight into the three international HCBS systems. Examples of frameworks, measures, and instruments used in these systems are provided in the Results section.

RESULTS

NQF staff identified a total of 261 measures, 394 measure concepts, and 75 instruments as being directly relevant to HCBS quality; these are displayed in the Compendium of Measures. NQF staff assigned measures, measure concepts, and instruments to the domains and subdomains of HCBS quality measurement defined by the Committee (see **Appendix D**).

Measures, Measure Concepts, and Instruments Across Domains

The majority of measures, measure concepts, and instruments identified fell within the domains of Service Delivery (n=256), System Performance (n=211), Effectiveness/Quality of Services (n=149), Choice and Control (n=132), and Health and Well-Being (n=82). No or few measures, measure concepts, or instruments were found related to Consumer Voice (n=0), Equity (n= 8), Community Inclusion (n=16), and Caregiver Support (n= 18). Although there are a number of measures, measure concepts, and instruments assigned to the domain of Choice and Control—the level to which individuals who use HCBS are able to choose their services and control how those services are delivered—no measures, measure concepts, or instruments were found within the domain of Consumer Voice—the level of involvement individuals who use HCBS have in the design, implementation, and evaluation of the HCBS system at all levels.

Table 1 displays the number of measures, measure concepts, and instruments mapped to each domain of measurement. As the domains are not mutually exclusive, some measures, measure concepts, and instruments were assigned to more than one domain or subdomain. In most cases, NQF, with input from the Committee Co-Chairs, assigned the measure, measure concept, or instrument to the domain to which it most closely aligned. In a few cases, the measure, measure concept, or instrument was assigned to up to three domains that closely aligned with the subject or purpose of the measure, measure concept, or instrument. Examples of measures and measure concepts were extracted from the compendium of measures and are shown in Table 2; examples of instruments are shown in Table 3.

TABLE 1. DOMAINS OF HCBS QUALITY MEASUREMENT AND ASSIGNED MEASURES, MEASURE CONCEPTS, AND INSTRUMENTS[a,b]

Domains for Measurement	Measures n=261	Measure Concepts n=394	Instruments n=75
Service Delivery	75	173	8
System Performance	42	166	3
Effectiveness/ Quality of Services	111	13	25
Choice and Control	17	61	34
Health and Well-Being	60	6	16
Workforce	10	65	6
Human and Legal Rights	4	28	1
Community Inclusion	4	15	7
Caregiver Support	4	3	11
Equity	4	4	0
Consumer Voice	0	0	0

[a] NQF staff deleted duplicate measures and measure concepts from the measure scan to the extent possible; however, due to retrieval and extraction from numerous sources, identifying and deleting duplicates from the scan was not straightforward, and some duplicate measures and measure concepts may exist.

[b] In some cases, information sources contained measures that were constructed from instrument items. These measures were extracted and included as measures, and the instrument as a whole is included under instruments.

TABLE 2. EXAMPLES OF MEASURES AND MEASURE CONCEPTS WITHIN DOMAINS AND SUBDOMAINS

Domain and Subdomain(s)	Title	Description	Numerator	Denominator
Service Delivery: Accessibility	Access to Plan Coordinators	Percentage of individuals who express that they are able to contact appropriate Person-Centered Plan Coordinators (PCPC) when needed	Number of service recipients who express they are able to contact the appropriate PCPC when needed	All service recipients who respond to the satisfaction survey
System Performance: Availability of services	Percent of children with special healthcare needs (CSHCN) receiving care in a well-functioning system	Percent of children with CSHCN receiving care in a well-functioning system (family partnership, medical home, early screening, adequate insurance, easy access to services, and preparation for adult transition)	Number of CSHCN ages 0 through 17 that received all components of a well-functioning system	Number of CSHCN ages 0 through 17
Effectiveness: Preferences met	Satisfaction with Performance of Service Providers	The percentage of waiver participants and family members responding to the National Core Indicators (NCI) survey who indicated satisfaction with the performance of their service providers	Waiver participants responding to the NCI survey with provider performance satisfaction	Waiver participants responding to the NCI survey[a]
Choice and Control: Self-direction	Long-Term Services and Supports (LTSS) Managed Care Organization (MCO) Process Measure	Percent increase in enrollees that receive participant-directed personal care.	Current number of enrollees receiving participant-directed personal care – previously reported # of enrollees receiving participant-directed care	Previously reported number of enrollees receiving participant-directed care
Health and Well-Being: Health status and wellness	Discharged to Community	Percentage of home health episodes after which patients remained at home	# of home health episodes where the assessment completed at the discharge indicates that the patient remained in the community after discharge	# of home health episodes of care ending with a discharge or transfer to inpatient facility during the reporting period

Domain and Subdomain(s)	Title	Description	Numerator	Denominator
Workforce: Skilled; demonstrated competencies when appropriate	Staff access to dementia-care training	Health and social care managers should ensure that all staff working with older people in the health, social care, and voluntary sectors have access to dementia-care training that is consistent with their roles and responsibilities	# of staff at care service or facility that receive specific dementia-care training on a regular basis, at least once a year	# of staff at care service/facility
Human and Legal Rights: Freedom from abuse and neglect	Community First Choice (CFC) Plan Recipient Abuse	The percentage of participants who are victims of substantiated abuse, neglect, or exploitation.	Participants who are victims of substantiated abuse, neglect, or exploitation	All CFC services recipients
Community Inclusion: Social connectedness and relationships; social participation	Proportion of adults with disabilities participating in social, spiritual, recreational, community, and civic activities to the degree that they wish	Increase the proportion of people with disabilities who participate in social, spiritual, recreational, community, and civic activities to the degree that they wish	# of people with disabilities who participate in social, recreational, community, and civic activities to the degree that they wish	# of people with disabilities
Caregiver Support: Training and skill building; caregiver well-being; caregiver and/or family assessment and planning	Care Plans for Caregivers	Caregiver care plans include interventions tailored to caregivers' needs and preferences (e.g., psycho-education and training courses, services and benefits, and dementia-care problem solving	# of caregivers of people with dementia offered psychosocial interventions, tailored to their needs and preferences	Total # of caregivers of people with dementia
Equity: Safe, accessible, and affordable housing	Housing status for individuals with an HIV diagnosis	Percentage of patients who were homeless or unstably housed in the12-month measurement period	# of persons with an HIV diagnosis who were homeless or unstably housed in the 12-month measurement period	# of persons with an HIV diagnosis receiving HIV services in the last 12 months

[a] The NCI is survey is broadly administered within states to people with intellectual and/or developmental disabilities (IDD) receiving state-funded IDD services. This measure concept was extracted from a state Medicaid HCBS waiver program and targets only waiver enrollees.

TABLE 3. EXAMPLES OF INSTRUMENTS

Domains	Title	Description
Choice and Control; Effectiveness/ Quality of Services; System Performance; Health and Well-Being	National Core Indicators – Aging and Disability (NCI-AD)	Developed to measure approximately 50 "indicators" of good outcomes of LTSS for older adults and adults with physical and other disabilities, excluding adults with intellectual and/or developmental disabilities
Effectiveness/Quality of Services; Choice and Control	Home Health Care Consumer Assessment of Healthcare Providers and Systems (CAHPS®) Survey	Designed to measure the experiences of people receiving services from Medicare-certified home health agencies that are provided by nurses and therapists, including physical, occupational, and speech-language therapists. The survey was designed to: (1) produce meaningful data on the patient's perspective to allow comparisons between agencies; (2) incentivize agencies to improve quality of care through public reporting; and (3) enhance accountability.
Choice and Control; Human and Legal Rights; Effectiveness/Quality of Services; Health and Well-Being	Money Follows the Person Quality of Life Survey	Designed to measure quality of life in seven domains: living situation, choice and control, access to personal care, respect/dignity, community integration/ inclusion, overall life satisfaction, and health status of people who have moved from institutional to community settings.
Choice and Control	Personal Experience Outcomes - Integrated Interview and Evaluation System (PEONIES)	Evaluates a broad set of individual experiences using person-centered language
Choice and Control	Personal Life Quality Protocol and Component Scales	This is a battery of instruments used to assess quality of life in individuals with intellectual or developmental disabilities. Outcomes Scales include California Development Evaluation Report (CDER) Behavior Scale - Adaptive Behavior; CDER Behavior Scale – Challenging Behavior; Individual Goal Progress; Decision Control Inventory; Integrative Activities; Productivity; Satisfaction; and Environmental Qualities.
Choice and Control; Effectiveness/ Quality of Services	Personal Outcome Measures® (POM)	Focuses on the choices people have and make in their lives. The Council and Quality and Leadership (CQL) developed a list of 21 personal outcomes to assess whether individuals are supported in a way that achieves the outcomes that are most important to them.

Examples of HCBS Quality Measurement Activities

Washington, Oregon, and Minnesota are the three states previously discussed in the section, Review of Federal Program Materials, in which measures from these programs were identified and added to the compendium of measures.

Washington, Oregon, and Minnesota are also each engaged in the innovative use of measures or instruments within their HCBS systems. Washington is the early stages of implementing two measure sets within the state—one for use in contracts with agencies providing HCBS services and the other for public and private health providers. Oregon and Minnesota are currently utilizing new instruments within their HCBS systems to evaluate consumer experience. Within England, Canada, and Australia, the implementation of quality frameworks and new initiatives surrounding the delivery of HCBS are currently underway. Details for each of these initiatives are included below.

Washington

Approximately 84 percent of Washington State Medicaid enrollees receive long-term services and supports in a home or community setting.[10] In recent years, Medicaid expansion and changes in enrollee needs (e.g., increasing proportion of enrollees with behavioral or substance abuse issues) have led to proposed restructuring of how the state delivers HCBS.[10] This proposed restructuring involves contracting with managed care and behavioral health organizations for the delivery of a variety of services. In 2013, state legislation mandated the development of a set of performance measures for inclusion in these types of contracts.[11] These measures address a variety of outcomes including improvement in client health status, improved client satisfaction with quality of life, and increased housing stability in the community. A steering committee consisting of representatives from community organizations, state agencies, and tribes identified 51 potential performance measures referred to as the Services Coordination Organizations (SCO) Accountability Measures.[11] This set includes "fully developed" measures (e.g., items from the Healthcare Effectiveness Data and Information Set) as well as those in earlier stages of conceptualization and development (e.g., suggested survey items on an individual's perceptions of respect). NQF extracted measures that met the inclusion and exclusion criteria and added them to the **Compendium of Measures**. Washington state agencies are working to select a subset of performance measures for initial adoption and inclusion in their 2016 contracts with providers.

In addition to the SCO Accountability Measure set, Washington state legislation also mandated the development of a statewide Common Set of Measures to be reported by public and private healthcare providers.[12] This measure set is not strictly focused on HCBS, as it contains more medically focused measures (e.g., the percent of the state population with influenza immunization or the percent of children with well-child visits), but it is meant to be used as a tool for helping to improve the effectiveness of healthcare purchasing and to assist in transforming the Washington state healthcare delivery system. The governor-appointed Performance Measures Coordinating Committee (PMCC) was charged with creating a measure set that is manageable in size and based on readily available healthcare insurance claims and/or clinical data. The set gives preference to nationally vetted measures, particularly those endorsed by NQF. In December of 2014, the Committee proposed a starter measure set containing 52 measures. This set included population measures (e.g., the percent of the state population with influenza immunization), clinical measures (e.g., the percent of children with well-child visits), and healthcare cost measures (e.g., the state's Medicaid per enrollee spending). This measure set is currently in its first year of implementation with 12 organizations submitting measurement data to the Washington State Health Care Authority.[13]

Oregon

In January 2014, CMS issued a Final Rule to ensure that Medicaid HCBS programs provide full access to the benefits of community living and offer services in the most integrated settings. Oregon has been working on the development and implementation of a transition plan that demonstrates how the various settings covered under its HCBS waivers and State Plan services meet the settings requirements promulgated in the Final Rule.[14,15] An important part of Oregon's transition plan is the use of consumer experience and provider self-assessment survey tools in assessing the various settings covered in their Medicaid-funded programs.

Most recently, residential settings (e.g., adult group homes) have undergone this assessment using experience tools developed by the Oregon Department of Human Services (DHS) and the Oregon Health Authority (OHA).[16] Individuals receiving services in these settings, or their representatives, were asked to complete an Individual Experience Assessment. This 49-item tool includes questions related to community access, choice of setting, personal finances, schedules, privacy, decorating options, access to food, visitation practices, and access to outside services. Providers in these residential settings were also asked to complete a Provider Self-Assessment Tool, also developed by DHS and OHA. The tool includes 73 items, asking providers to indicate how closely their setting meets the requirements of the Final Rule. Data collection on both the Individual Experience Assessment and Provider Self-Assessment Tool was completed in October of 2015.[16] In 2016, the state will share survey results with providers and use the results to determine what changes, if any, need to be made in order to bring the provider and the setting into compliance with the Final Rule.

Minnesota

Minnesota has developed a strong network of home and community-based services through a combination of federally (e.g., Medicaid Section 1915(c) Minnesota Elderly Waiver) and state-funded programs (e.g., Alternative Care Program, Consumer Support Grants Program) on which a wealth of data are collected and reported. To assess the adequacy of this network and inform policy decisionmaking, the Minnesota State Legislature has mandated that a Gaps Analysis Study on several of these programs be completed every two years.[17] Information is gathered from provider agencies, consumers, and advocates about perceived barriers, availability, and use of services. For residents receiving care through Medicaid, almost two-thirds are enrolled in a managed care program. The quality and effectiveness of these programs are monitored through the collection of Healthcare Effectiveness Data and Information Set (HEDIS)[d] and Consumer Assessment of Healthcare Providers and Systems (CAHPS®)[e] data, and programs are mandated to engage in annual performance improvement projects.[18]

In addition to these activities, Minnesota has been a leader in testing new ways of capturing consumer perspectives on HCBS through its participation in the piloting of the National Core Indicator-Aging and Disabilities (NCI-AD) survey. The National Core Indicators (NCI) are a "…standard set of measures used across states to assess the outcomes of services provided to individuals and families," and NCI surveys

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[d] The National Committee for Quality Assurance developed HEDIS to assess various dimensions of healthcare (e.g., medication management, preventative screenings) and is often used to assess the performance of health plans.

[e] The Agency for Healthcare Research and Quality developed CAHPS® as a means to capture consumers' experiences with their health care providers and systems.

are the method by which data are collected for the calculation of these indicators.[19] Example indicators include the proportion of adults with developmental disabilities receiving support services who have a paid job in the community and the proportion of families who feel that services and supports have helped them to better care for their family member living at home.[19] The NCI-Adult Consumer and NCI-Family surveys were first developed in 1997, and states have the option to the use these instruments for the assessment of services delivered to individuals with intellectual and development disabilities. Currently, 39 states are administering these surveys. In 2012-2013, Minnesota was one of three states to pilot the newly developed NCI-AD survey. For this pilot study, Minnesota administered the survey to approximately 400 older adults and individuals with physical disabilities receiving publicly funded, long-term care services. Results of the pilot study supported the validity and reliability of the survey. Starting in fiscal year 2016, Minnesota will be using the NCI-AD in a number of HCBS programs including its Alternative Care Program and Older Americans Act funded services.[20]

England

In England, the Department of Health is responsible for the overall governance of the health and social care system. Within this system, home and community-based services are considered "social care."[21] Health services are available to all citizens through the National Health Service (NHS), but the NHS only funds certain kinds of HCBS (e.g., home care, home modification and equipment). However, the 2014 Care Act implemented a variety of changes that will shift how HCBS is delivered and funded, particularly in terms of providing individuals who use HCBS and their caregivers more control over their care and the services they receive under social care programs.

The National Institute for Health and Clinical Excellence (NICE) creates guidelines for quality standards and performance measurement in health and social care. Private and publicly funded HCBS are regulated by the Care Quality Commission (CQC), which ensures adherence to basic quality standards. Some of these quality standards include person-centered care, dignity and respect, and consent.[22] The Adult Social Care Outcomes Framework, first published in 2011, provides timely and relevant information about the quality of HCBS to individuals who use these services and their caregivers.[23] The framework also provides local governments with information to assist in identifying opportunities for improvement and assessing the success of local efforts in improving outcomes. At a regional level, the framework allows for benchmarking and exchange of best practices. At a national level, the framework captures the performance of the adult HCBS system (i.e., all adults who use HCBS) as a whole and informs national policy. The most recent framework focuses on measures pertaining to the four domains highlighted in Table 4.[23]

TABLE 4. ADULT SOCIAL CARE OUTCOMES FRAMEWORK DOMAINS AND EXAMPLE MEASURES – ENGLAND

Domains	Example Measures
Domain 1: Enhancing quality of life for people with care and support needs	• Proportion of people using social care who receive self-directed support, and those receiving direct payments • Carer-reported quality of life • Proportion of adults with a learning disability in paid employment
Domain 2: Delaying and reducing the need for care and support	• Permanent admissions to residential and nursing care homes, per 100,000 population • Proportion of older people (65 and over) who were still at home 91 days after discharge from a hospital into rehabilitation services • Delayed transfers of care from hospital, and those which are attributable to adult social care
Domain 3: Ensuring that people have a positive experience of care and support	• Overall satisfaction of people who use services with their care and support • The proportion of carers who report they should have been included or consulted in discussion about the person they care for • The proportion of people who use services and carers who find it easy to find information about support
Domain 4: Safeguarding adults whose circumstances make them vulnerable and protecting them from avoidable harm	• The proportion of people who use services who feel safe • The proportion of people who use services who say that those services have made them feel safe and secure • The proportion of completed safeguarding referrals where people report they feel safe

Canada

In Canada, HCBS is referred to as "*home care*" and is defined as "as array of services for people of all ages, provided in the home and community setting, that encompasses health promotion and teaching, rehabilitation, support and maintenance, social adaptation and integration, end-of-life care, and support for family caregivers."[24] HCBS is organized and delivered through federal, provincial, or territorial governments or by regional health authorities. HCBS are not considered insured services under the Canada Health Act—the law that sets pan-Canadian standards for the administration, delivery, and financing of healthcare. As a result, provinces and territories can choose to fund HCBS, but are not required by the federal government to do so.[21] Nevertheless, all provinces and territories provide some level of funding for HCBS, but coverage, eligibility criteria, and payment models are highly variable.[25] Public funding for HCBS either comes through government contracts with public or private providers or through stipends to consumers to direct their own care.[21]

Although there is no national legislated quality framework for HCBS in Canada, at a provincial level, a number of jurisdictions are involved in quality measurement initiatives. One example is Ontario's Excellent Care for All Act (2010) which requires HCBS organizations to provide the provincial quality council with an annual quality improvement plan in order to facilitate reporting and comparison of a minimum set of quality measures.[24] The measures are aligned to six attributes of quality: accessible, effective, safe, patient-centered, efficient, and population-health focus[26] and are detailed in Table 5. There is also provincial work on quality measurement targeting HCBS populations. For instance, Community Living British Columbia (CLBC)—a provincial agency funding HCBS for people with developmental disabilities and their families—is currently developing a quality framework that links dimensions of quality to CLBC values, and identifies possible performance measures within each quality dimension (e.g., percentage of individuals receiving services reporting current employment who retained employment for one year).[27]

TABLE 5. ONTARIO HOME CARE QUALITY MEASURES – CANADA

Attribute	Theme	Measures
Accessible	Waiting for nursing services	Percentage of home care patients who received their first nursing visit within five days of the date they were authorized for nursing services
	Waiting for personal support services for complex patients	Percentage of home care patients with complex needs who received their first personal support visit within five days of the date they were authorized for personal support services
Effective	Incontinence	Percentage of home care patients who have newly developed bladder incontinence or whose bladder functioning has not improved since their previous assessment
	Communication	Percentage of home care patients with a new problem communicating or existing communication problem that did not improve since their previous assessment
	Hospital readmissions	Percentage of home care patients with unplanned hospital readmissions within 30 days of referral from hospital to Community Care Access Centre after acute hospital discharge
Safe	Falls	Percentage of home care patients who fell in the last 90 days
	Pressure ulcers	Percentage of home care patients with a new pressure ulcer (stage 2 to 4)
Patient-Centered	Patient satisfaction (provincial/ CCAC)	Percentage of home care patients who were satisfied with their care from both care coordinators and service providers
	Patient satisfaction (provider)	Percentage of home care patients who were satisfied with the services provided by their service provider
Efficient	Emergency department visits	Percentage of home care patients who had unplanned emergency department visits within 30 days from referrals from hospital to Community Care Access Centre after acute hospital discharge
	Long-term care placement	Percentage of home care patients placed in long-term care who could have stayed home or somewhere else in the community
Population Health Focus	Vaccination	Percentage of home care patients who have not received influenza vaccination in the past two years.

Australia

In Australia, the Department of Health oversees the delivery of medical services (e.g., care in public hospitals, clinics) while home and community-based services, referred to as "home and community care," are overseen by the Department of Social Service (DSS).[28] The universal public health insurance program, Medicare, covers the cost of medical services offered through the public sector and subsidizes HCBS services to individuals who qualify for specific programs with program participants usually having to pay some out-of-pocket expenses. The delivery of medical and home and community care services is the responsibility of the states and territories, while issues related to funding and policy development are largely the responsibility of the federal government.[21]

Two major programs providing HCBS to Australians are the Home and Community Care Programme and the newly enacted National Disability Insurance Scheme. The Home and Community Care Programme includes Community Aged Care Packages, Extended Aged Care at Home, and Extended Aged Care at Home Dementia and the National Respite for Carers Program that primarily target older Australians who are at risk for declining independence. Services provided through these programs include nursing care, allied health care, meal delivery, personal care, respite, and transportation. Programmatic quality is guided by the Community Care Common Standards, which are maintained and monitored by DSS.[29] Three overarching standards (effective management, appropriate access and service delivery, and service user rights and responsibilities) as well as 18 expected outcomes guide the quality review process that service providers must participate in every three years. During this process, providers complete a self-assessment tool wherein they must demonstrate their compliance with the three standards as well as their achievement of the 18 expected outcomes. Providers are not mandated to report specific measures, but examples of potential measures providers can use are listed in Table 6.

TABLE 6. COMMUNITY CARE COMMON CORE STANDARDS – AUSTRALIA

Standard	Expected Outcome	Example Performance Measure
Effective Management	The service provider has effective information management systems in place.	Proportion of staff provided with training/education on the policies and procedures
Appropriate Access and Service Delivery	Each service user and/or their representative, participates in the development of a care/service plan that is based on assessed needs and is provided with the care and/or services described in their plan.	Proportion of staff provided with training/education on the principles of service delivery
Service User Rights and Responsibilities	The independence of service users is supported, fostered, and encouraged.	Proportion of staff provided training/education on promoting and fostering independence

The National Disability Insurance Scheme (NDIS) is the result of the National Disability Insurance Scheme Act of 2013 and represents a new approach to providing services to individuals with significant and permanent disabilities who are under the age of 65.[30] In this new scheme, funding allocations for services are based on individuals' needs rather than through block grants to specific providers. This approach is meant to facilitate greater consumer choice and control and result in service delivery that is determined by the needs of the consumer, not the availability of providers or services. Services covered via the NDIS include but are not limited to accommodation support, community access, respite, supported employment, and communication support.

An NDIS Outcomes Framework is under development, and the framework domains are shown in Table 7.[31] Preliminary outcome measures associated with these domains are currently undergoing pilot testing.

TABLE 7. DOMAINS OF THE NDIS OUTCOMES FRAMEWORK – AUSTRALIA

Adults: Participant Domains	Adults: Family Domains
• Choice and control • Home • Work • Daily activities • Health and well-being • Social, community, and civic participation • Relationships • Lifelong learning	• Families have the support they need to care • Families know their rights and advocate effectively for their family member with disability • Families are able to gain access to desired services, programs, and activities in their community • Families have successful plans • Parents enjoy health and well-being

NEXT PHASE OF PROJECT WORK

The Committee will convene at a web meeting on January 29, 2016, to discuss the results of the synthesis of evidence and environmental scan, as well as the public comments received on this report. The Committee will meet again on March 30-31, 2016, for a two-day in-person meeting at NQF headquarters in Washington, DC, to continue to discuss the availability of evidence for measurement, review existing measures and measure concepts, and elaborate on potential new measurement concepts for development. They will also discuss gaps in measurement and prioritize opportunities for future measure development. The priorities will be selected based on the areas of greatest need for quality improvement, feasibility of measurement, and the availability of existing measures. The Committee will also identify promising measure concepts and instruments that demonstrate potential for being transformed into performance measures.

FUTURE MILESTONES

This is the second of three interim reports. The next report, to be issued in the summer of 2016, will include recommendations from the Committee on priorities for furthering HCBS quality measurement. Following the completion of each interim report, there will be a 30-day public comment period. Comments will be made publicly available. Committee members will review comments and use them to inform their ongoing work. However, none of the interim reports will be revised. Rather, the interim reports will build on each other and culminate in a final report that will be submitted to HHS in September 2016.

ENDNOTES

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APPENDIX A:
HCBS Committee, NQF Project Staff, and HHS Advisory Group

COMMITTEE MEMBER NAME	ORGANIZATION
Joe Caldwell, PhD (Co-chair)	National Council on Aging
H. Stephen Kaye, PhD (Co-chair)	University of California San Francisco
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Suzanne Crisp	National Resource Center for Participant Directed Services
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Ari Houser, MA	AARP Public Policy Institute
Patti Killingsworth	Bureau of TennCare
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Sarita Mohanty, MD, MPH, MBA	Kaiser Permanente Northern California
Gerry Morrissey, MEd, MPA	The MENTOR Network
Ari Ne'eman	Autistic Self Advocacy Network
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HHS ADVISORY GROUP	FEDERAL AGENCY
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Ellen Blackwell	Centers for Medicare & Medicaid Services
Venesa Day (Oct 2014 – Nov 2015) Elizabeth Ricksecker (Nov 2015 – Present)	Centers for Medicare & Medicaid Services
Jamie Kendall	Administration for Community Living
Lisa Patton	Substance Abuse and Mental Health Services Administration
D.E.B. Potter	Office of the Assistant Secretary for Planning and Evaluation
Michael Smith	Centers for Medicare & Medicaid Services

APPENDIX B:
Inclusion/Exclusion Criteria, Impact Ratings, and Evaluation Criteria

Inclusion/Exclusion Criteria for Evidence

Included	Excluded
• Literature published after 2000 OR originally published prior to 2000 and still current (as identified by being in use or cited in recent resources) AND • Pertains to a best practice or challenge related to the delivery of or outcomes of HCBS AND • Applies to a specific HCBS population, setting, or service	• Published before 2000 and not current OR • Pertains to institutional care OR • Pertains to international efforts besides those identified by AG/ Federal Liaisons OR • Not available in English

Impact Ratings for Sources in Annotated Bibliography

Impact	The extent of the range of costs imposed (e.g., economic, impaired function, mortality), including effects on consumers, families, communities, and the nation
Improvability	The extent of the gap between current practice and evidence-based best practice and the likelihood that the gap can be closed and conditions improved through measurement and change; and the opportunity to achieve dramatic improvements in broad quality aims such as safety, person-centeredness, timeliness, efficiency, equity, and effectiveness
Inclusiveness	Equity, as defined by the relevance of an area to a broad range of people with regard to age, gender, socioeconomic status, and ethnicity/race; representativeness, as defined by the generalizability of associated quality improvement strategies to many types of populations across the spectrum of HCBS; and reach, as defined by the breadth of change effected through such strategies across a range of settings and providers

Inclusion/Exclusion Criteria for Measures, Measure Concepts, and Instruments

Included	Excluded
• Measures directly relevant to HCBS currently in use or proposed for use (have a specific numerator and denominator, and have undergone scientific testing) • Addresses a long-term physical, cognitive, and/or behavioral health need or disability • Delivered in the home or other integrated community setting • Applies to an HCBS target population • Applies to an HCBS service or support[a] • Maps onto an HCBS domain • Measure concepts (metrics that have a specific numerator and denominator, but have not undergone testing) directly relevant to HCBS • Psychometrically tested and validated surveys, scales, or other instruments directly relevant to HCBS, especially consumer and caregiver experience with HCBS and quality of life – Testing must be in the HCBS population for which the instrument is designed	• Sources published prior to 2000 • Measures or measure concepts without a specific numerator or denominator • Measures that pertain to institutional care/ setting (e.g., hospitals and nursing homes) • Measures that pertain to international efforts beyond Canada, Australia, and the UK

[a] Centers for Medicare & Medicaid Services (CMS). The HCBS taxonomy: a new language for classifying home- and community-based services website. http://www.cms.gov/mmrr/Briefs/B2014/MMRR2014_004_03_b01.html. Last accessed July 2015.

Evaluation Criteria for Measures and Measure Concepts

Evaluation Criteria	Rating Scales
1: Scientific evidence and psychometric testing	**A** – Reliability and/or validity testing documented within the information source from which the measure was extracted. **B** – Evidence of some instrument testing. This could include focus groups, or cognitive-, pilot- or pre-testing the instrument with respondents (no quantifiable statistical measure of testing results reported). **I** – No documented evidence of psychometric testing in the source from which the measure or measure concept was extracted.
2: HCBS populations of interest	**A** – Designed/tested for more than one HCBS population (e.g., people with intellectual, developmental and/or physical disabilities, mental disorders, HIV/AIDS, brain injury) **B** – Designed/tested for one HCBS population **I** – The measure was: a. Designed/tested for the general population not receiving HCBS (i.e., no relationship to LTSS) OR b. Designed/tested for persons receiving institutional care (nursing home, hospital, etc.)
3: Feasibility of data collection (data source and data collection methods)	**A** – Requires administrative/clinical data collection from single organizational source (e.g., claims, critical event reporting systems) **B** – Requires survey data collection from a single survey respondent or chart review from a single source **C** – Requires administrative/clinical data from multiple organizational sources **I** – Requires survey data collection from multiple respondents to construct the measure about a single person
4: Prevalence of use	**A** – Use or intended use by a federal government agency or national entity **B** – Use or intended use by two or more programs/entities (including state/local) **C** – Use or intended use by one program/entity (including managed care organizations) **I** – No indication of use

APPENDIX C:

Keywords for Literature Search

Databases were searched first using combinations of the primary and population keywords followed by an iterative cycle of adding Framework Domain keywords to the Primary and Population keyword combinations. A final search used the combinations of the primary and population keywords with the subdomain and HCBS concept keywords.

Tier 1. Primary Keywords

- Home & community based services
- Long term services and supports
- Evidence based practices
- Performance
- Quality
- Measure/measurement
- Process
- Measure concept
- Structure
- Outcome(s)

Tier 2. Population Keywords

- Intellectual or Developmental Disabilities
- Mental Retardation (older terminology)
- Substance Abuse
- Substance Use
- Physical disabilities
- Family caregivers
- Dually Eligible
- Older persons (65+ years of age)
- Senior/Elderly
- Alzheimer (AD)/ Dementia
- Serious Emotional Disturbance
- Serious Mental Illness
- Mental health
- Behavioral Health

Tier 3. Framework Domain Keywords

- Workforce
- Direct Support workforce
- Direct Service workforce
- System performance
- Service delivery
- Consumer Voice
- Community inclusion
- Equity
- Choice & Control
- Individual Choice and Control
- Personal Choice and Control
- Caregiver support
- Health & well-being
- Human & Legal rights
- Effectiveness/ quality of services

Tier 4. Framework Subdomain and HCBS Concepts from Statement of Work Keywords[a]

Workforce

- Capacity
- Availability
- Skilled
- Competent
- Respectful
- Compensated
- _Stability*_
- _Recruitment*_
- _Retention*_
- _Training*_

Consumer Voice

- Engagement
- Participation
- Person-centered/ driven
- Consumer-centered/ driven
- Activation
- Responsiveness
- Accountability
- _Satisfaction*_
- _Experience*_
- _Quality of Life*_
- _Perception*_
- _Stakeholder*_
- _See also Choice and Control*_

Choice and Control

- Freedom
- Dignity
- Goals & preferences
- Self-direction
- Accountability
- Dignity of risk
- _Financial obligations*_
- _Consumer-directions*_
- _Self-determination*_
- _Consumer Control*_
- _Self-reliance*_
- _Independence*_
- _See also Human and Legal Rights*_

Human & Legal Rights

- Dignity
- Respect
- Informed consent
- Abuse
- Neglect
- Coercion
- Restraint
- Safety
- _(Limited/Person/ Financial) Guardianship*_
- _Decision Making*_
- Petitioner
- (Durable) Power of Attorney
- Supported Decision Making

System Performance

- Rebalancing
- Program design
- Data
- Outcomes
- Resource allocation
- Financing
- Evidence based practice
- _Emergency preparedness*_
- _Adverse Health events*_
- _Affordability*_
- _Cost effectiveness*_
- _Quality improvement*_
- _Timely*_
- _Fidelity*_
- _Respect*_
- _Dignity*_
- _Survey*_

Community Inclusion

- Enjoyment
- Employment
- Education
- Social connectedness & participation
- Accessible environment
- Transportation
- Mobility
- Housing
- Home
- Transition
- Affordable
- Person-centered
- Access to services

Caregiver Support

- Caregiver well-being
- Resources
- Caregiver assessment
- Caregiver planning
- Caregiver compensation
- Respite
- Education
- Reimbursement
- Relief
- Burden

Effectiveness/ Quality of Services

- Goal achievement
- Needs & preferences met
- Skill assessment
- Goal & preferences monitoring
- _Staff-consumer relationship*_
- _Experience*_
- _Timeliness*_
- _Coordinated*_
- _Adequate*_
- _Responsive*_

Service Delivery

- Program service accessibility
- Assessment
- Needs & service alignment
- Service coordination
- _Assistive technologies*_
- _Technology infrastructure*_
- _Medical, nursing and nutritional services*_
- _Case management*_

Equity

- Disparity reduction
- Access
- Waiting lists
- Housing

Health & Well-being

- Physical, emotional and cognitive functioning
- Social well-being
- Spirituality
- Behavioral health

Payers, Programs, and/ or Government Entities

- Medicare
- Medicaid
- Managed Medicaid Waiver programs
- 1915 (c),1915 (i) 1915(k), 1915(j), Community First Choice, 1115
- Balancing Incentive Program
- Health homes
- Money follows the person
- Administration on Community Living

[a] Italicized keywords marked with an asterisk are those added by NQF staff to ensure appropriate and relevant information sources were retrieved during the literature search.

Measure Data Elements

The following data elements were extracted from information sources for each measure, measure concept and instrument when information was available.

Data Element	Description
Title	Name of measure or measure concept.
Description	Measure description, if available.
Numerator	Numerator statement, if available
Denominator	Denominator statement, if available
Measure Type	Measure type based on NQF taxonomy
HCBS Focus	Service type (e.g., day program, personal care, informal care, respite, self- directed services, etc.)
Target Population	Group included in measure denominator, if available (e.g., ID/DD, brain injury, older adults, mental disorder(s), etc.)
Payer	Public, Private, Any
Lifecycle Stage	Best determination of stage of measure development: Measure or Measure Concept
Measure Developer or Steward	Organization responsible for developing or maintaining the measure or concept, if available
Service Setting	Location of the delivered service/element, if available (e.g., home, school, day program, employment site)
Level of Analysis	Entity being held accountable by the measure, if available (e.g., state, individual provider, agency, consumer)
Data Source	Data source for measure information (e.g., consumer survey, administrative data, registry)
NQF #	Measures currently or previously endorsed by NQF include an NQF number
NQF Endorsement Status	Status of NQF endorsement for measures with an NQF number
HHS Inventory #	Measures and concepts include a numeric identifier imported from the HHS Inventory
Framework Domain	Measures and concepts categorized to priority gap areas based on HCBS committee framework
Framework Subdomain	Measures and concepts categorized to priority gap areas based on HCBS committee framework
Information Source	The research database or specific source of the measure or concept information (not data source)
Evaluation Criteria Rating: scientific evidence	Rating of A, B, or I
Evaluation Criteria Rating: HCBS populations	Rating of A, B, or I
Evaluation Criteria Rating: feasibility of data collection	Rating of A, B, C, or I
Evaluation Criteria Rating: prevalence of use	Rating of A, B, C, or I
Potential Duplicate	Potentially duplicate measures and concepts to be tagged and filtered out for easier viewing
NQMC #	Measures and concepts include a numeric identifier if imported from AHRQ’s National Quality Measure Clearinghouse

APPENDIX D:

Definition, Characteristics, Domains, and Subdomains

Operational Definition of HCBS

The term “home and community-based services” (HCBS) refers to an array of services and supports that promote the independence, well-being, self-determination, and community inclusion of an individual of any age who has significant, long-term physical, cognitive, and/or behavioral health needs and that are delivered in the home or other integrated community setting.

Characteristics of High-Quality HBCS

1. Provides for a person-driven system that optimizes individual choice and control in the pursuit of self-identified goals and life preferences
2. Promotes social connectedness and inclusion of people who use HCBS in accordance with individual preferences
3. Includes a flexible range of services that are sufficient, accessible, appropriate, effective, dependable, and timely to respond to individuals’ strengths, needs, and preferences and are provided in a setting of the individual’s choosing
4. Integrates healthcare and social services to promote well-being
5. Promotes privacy, dignity, respect, and independence; freedom from abuse, neglect, exploitation, coercion, and restraint; and other human and legal rights
6. Ensures each individual can achieve the balance of personal safety and dignity of risk that he or she desires
7. Supplies and supports an appropriately skilled workforce that is stable and adequate to meet demand
8. Supports family caregivers
9. Engages individuals who use HCBS in the design, implementation, and evaluation of the system and its performance
10. Reduces disparities by offering equitable access to and delivery of services that are developed, planned, and provided in a culturally sensitive and linguistically appropriate manner
11. Coordinates and integrates resources to best meet the needs of the individual and maximize affordability and long-term sustainability
12. Receives adequate funding to deliver accessible, affordable, and cost-effective services to those who need them
13. Supplies valid, meaningful, integrated, aligned, accessible, outcome-oriented data to all stakeholders
14. Fosters accountability through measurement and reporting of quality and outcomes

Domains of HCBS Quality Measurement

Domains for Measurement	Description of Domain
Workforce	The adequacy and appropriateness of the provider network and HCBS workforce
Consumer Voice	The level of involvement individuals who use HCBS have in the design, implementation, and evaluation of the HCBS system at all levels
Choice and Control	The level to which individuals who use HCBS are able to choose their services and control how those services are delivered
Human and Legal Rights	The level to which the human and legal rights of individuals who use HCBS are promoted and protected
System Performance	The level of accountability within the HCBS system and the extent to which it operates efficiently, ethically, and is able to achieve desired outcomes
Community Inclusion	The level to which HCBS integrates individuals into their communities and fosters social connectedness
Caregiver Support	The level of support (e.g., financial, emotional, technical) available for the paid and unpaid caregivers of individuals who use HCBS
Effectiveness/Quality of Services	The level to which HCBS services are able to produce intended outcomes
Service Delivery	Aspects of services that enable a positive consumer experience (e.g., accessibility, respect, dependability, well-coordinated)
Equity	The level to which HCBS is equitability delivered and made available to a broad array of individuals who need long-term supports
Health and Well-Being	The level of integration between healthcare and other supportive services to promote holistic wellness

Draft Subdomains of HCBS Quality Measurement

Domains for Measurement	Subdomains Corresponding to Each Domain
Workforce	Sufficient numbers and appropriately dispersed; dependability; respect for boundaries, privacy, consumer preferences, and values; skilled; demonstrated competencies when appropriate; culturally competent, sensitive, and mindful; adequately compensated, with benefits; safety of the worker; teamwork, good communications, and value-based leadership
Consumer Voice	Meaningful mechanism for input (e.g., design, implementation, evaluation); consumer-driven system; breadth and depth of consumer participation; level of commitment to consumer involvement; diversity of consumer and workforce engagement; and outreach to promote accessible consumer engagement
Choice and Control	Choice of program delivery models and provider(s) including self-direction, agency, particular worker(s), and setting(s); personal freedoms and dignity of risk; achieving individual goals and preferences (i.e., individuality, person-centered planning); self-direction; shared accountability
Human and Legal Rights	Delivery system promotes dignity and respect; privacy; informed consent; freedom from abuse and neglect; optimizing the preservation of legal and human rights; sense of safety; system responsiveness
System Performance	Consumer engagement; participatory program design; reliability; publicly available data; appropriate and fair resource allocation based on need; primarily judged by the aggregate of individual outcomes; waiting lists; backlog; financing and service delivery structures; availability of services; efficiency and evidence based practices; data integrity
Community Inclusion	Enjoyment or fun; employment, education, or productivity; social connectedness and relationships; social participation; resources to facilitate inclusion; choice of setting; accessibly built environment
Caregiver Support	Training and skill-building; access to resources (e.g., respite, crisis support); caregiver well-being (e.g., stress reduction, coping); caregiver and/or family assessment and planning; compensation
Effectiveness/Quality of Services	Goals and needs realized; preferences met; health outcomes achieved; technical skills assessed and monitored; technical services delivered; team performance; rebalancing
Service Delivery	Accessibility (e.g., geographic, economic, physical, and public and private awareness or linkage); appropriate (e.g., services aligned with needs and preferences, whether goals are assessed); sufficiency (e.g., scope of services, capacity to meet existing and future demands); dependable (e.g., coverage, timeliness, workforce continuity, knowledge of needs and preferences, and competency); timely initiation of services; coordination (e.g., comprehensive assessment, development of a plan, information exchange between all members of the care team, implementation of the plan, and evaluation of the plan)
Equity	Reduction in health and service disparities; transparency of resource allocation; access or waiting list; safe, accessible, and affordable housing; availability; timeliness; consistency across jurisdictions
Health and Well-Being	Physical, emotional, and cognitive functioning; social well-being, spirituality; safety and risk as defined by the consumer; freedom from abuse, neglect, and exploitation; health status and wellness (e.g., prevention, management of multiple chronic conditions); behavioral health

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A State Policy Framework for Integrating Health and Social Services

Tricia McGinnis, Maia Crawford, and Stephen A. Somers

Abstract Recognizing that health is determined by a variety of interrelated factors, states are looking to connect health care, public health, and social services to help achieve improved population health, better care, and reduced cost of care. This issue brief describes three essential components for integrating health, including physical and behavioral health services and public health, and social services: 1) a coordinating mechanism, 2) quality measurement and data-sharing tools, and 3) aligned financing and payment. It also presents a five-step policy framework to help states move beyond isolated pilot efforts and establish the infrastructure necessary to support ongoing integration of health and social services, particularly for Medicaid beneficiaries.

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OVERVIEW

Despite considerable obstacles associated with reengineering the nation's medically oriented health care system, Medicaid agencies are beginning to explore health delivery models that connect patients directly to community-based public health and social services. In doing so, they are looking to take advantage of both new and existing funding strategies and Medicaid policy options to promote more effective service linkages.

To help guide these efforts, this issue brief details three components necessary for an integrated system of health and social services:

1. A coordinating mechanism responsible for managing collaboration across services.
2. Quality measurement and data-sharing tools to track outcomes and exchange information.
3. Payment and financing methods that support and reward effective service integration.

Our five-step framework is intended to help states develop an implementation plan that addresses the infrastructure requirements, incentives, and decision-making authority needed to support health and social services integration. Elements of this brief were gleaned from state officials and health policy experts through interviews and group discussions.

BACKGROUND

There is growing recognition that social factors—such as individual behavior, socioeconomic status, and the physical environment—have a greater impact on health outcomes than medical care.[1] Nevertheless, most health care expenditures are for medical services. Further, the planning, financing, and delivery of health care, public health, and social services often occur in isolation. In response to this misalignment of resources, a new vision for integrating health and social services is emerging. Such a system would coordinate, finance, and assess a wide range of services that impact health, including social supports, housing, economic opportunities, education, public health, and community resources.

Federal and state-level policy environments appear favorable for integrating health and social services for many reasons: 1) the Affordable Care Act (ACA) extends Medicaid to millions of vulnerable individuals primed to benefit from integrated services; 2) the ACA's focus on delivery system and payment reform and the creation of the Center for Medicare and Medicaid Innovation has led to the spread of innovative care models like accountable care organizations (ACOs) that promote more coordinated, patient-centered care; and 3) providers are increasingly supportive of approaches that address patients' unmet social needs.[2] New efforts to integrate health and social services can draw lessons from existing programs that coordinate physical and behavioral health and social services.

ADVANCING HEALTH AND SOCIAL SERVICES INTEGRATION: PRINCIPLES FOR STATES AND PARTNERS

- Demonstrate a shared commitment to the integrated vision;
- Increase community accountability for population health outcomes that reflect physical, mental, and social well-being;
- Use financing strategies that foster accountability for outcomes; and
- Use population health data to track performance and refine incentive strategies.

However, policymakers must contend with some challenges. For example, states' health and social services programs often are fragmented because of federal financing streams, poor interagency communication, and insufficient IT capacity. There is also little evidence to support a positive return on investment (ROI) for integrating services.

ESSENTIAL COMPONENTS FOR INTEGRATING HEALTH AND SOCIAL SERVICES

State leaders can target planning efforts by focusing on three core components for integrating health and social services: a coordinating mechanism, quality measurement and data-sharing tools, and aligned financing and payment methods. States pursuing integration of health and social services will need to develop each of these components at the state, community, and provider levels (Exhibit 1).*

1. A Coordinating Mechanism

States can identify or develop a statewide "integrator" to assume responsibility for ensuring coordination and communication across state-level services. This coordinating entity—a state agency, task force, or nongovernmental organization—can engage partners, recommend policy and practice changes, promote information exchange, and assess data.[3] Maryland's Office of Health Reform, for example, facilitates interagency collaboration on state health initiatives. California created a Health in All Policies Task Force, bringing together 19 state agencies to develop health improvement recommendations.

Coordinating mechanisms are also important at the community level. David Kindig, at the University of Wisconsin–Madison, developed the concept of a "health outcomes trust," a local entity that receives financial incentives to coordinate services across organizations to address the social determinants of health.[4] This entity could disseminate health data, establish shared goals and activities, and engage local residents.[5] Prevention Institute, a national nonprofit,

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* Note that this brief focuses on the state and community levels only.

Exhibit 1. Components to Support Health and Social Services Integration by Stakeholder

Level	Coordinating Mechanisms	Quality Measurement and Data-Sharing Tools	Financing and Payment Methods
State	Integrator agencies/entities Formalized interagency arrangements	Population health metrics Integrated claims database/analysis	Braided or blended agency financing Wellness trusts Multipayer coordination
Community	Health outcomes trusts Accountable care communities	Integrated population health/quality report cards	Communitywide global services payment Community benefit funds Global capitation
Provider	Accountable care organizations Medicaid health homes	E-referrals Integrated patient-level data-sharing	Bundled payments Shared savings Care management per-member per-month Global capitation

Source: Authors' analysis.

has proposed community-centered health homes, in which local health institutions serve as a coordinating entity for collaborative health improvement efforts, like building walking paths, improving food access, and minimizing environmental hazards.[6] Community-based ACOs and newly emerging accountable care communities serve a coordinating function by taking responsibility for providing and paying for a range of services beyond medical care.[7]

2. Quality Measurement and Data-Sharing Tools

Efforts to meaningfully integrate health and social services should be supported by a robust set of tools to measure health outcomes and costs, as well as the capacity to share data, link services, and evaluate and improve programs.

Quality Measurement

It is important for states to choose metrics that reflect realistic quality and accountability goals, understanding that it may take years or decades to fully influence outcomes. Population health metrics could include: life expectancy from birth, condition-specific life expectancy changes, and self-reported levels of health.[8] The Institute of Medicine (IOM) recommends establishing population health measures that are usable for assessing various populations, rigorous, and widely accepted.[9]

Some states are collecting and analyzing health data from sources outside clinical settings, then producing report cards on state or community health.[10] For example, Maryland publishes outcomes on 39 health measures, such as healthy social environments and safe physical

STATE-BASED MODELS OF HEALTH AND SOCIAL SERVICES INTEGRATION

Minnesota's Hennepin Health: This health plan integrates health care, public health, community resources, behavioral health, and social services for high-risk, Medicaid-eligible adults. It is financed by an up-front payment for all Medicaid services, with blending of additional county-based social services funds.

Vermont's Support and Services at Home: This program combines supportive housing with medical services to help Medicare beneficiaries remain in their communities. It offers onsite nursing, care coordination, and supportive community activities. It is funded by a per-member per-month fee through a Medicare demonstration program.

Maryland's Health Enterprise Zones: Five geographic areas in Maryland with high health disparities rates receive state funding to test innovative, multisector programs. Examples include establishing a "health care transportation route" to address rural access barriers; a patient-centered medical home in a senior housing complex; and healthy living activities.

environments.[11] Connecticut created the Health Equity Index, a community-level electronic tool that measures the social, political, economic, and environmental conditions affecting health.[12]

Data-Sharing Systems

Up-front technology investments are needed to support integration efforts, accurately measure program impact, and inform future investment decisions. These include building an integrated data system and establishing the IT supports necessary for implementation. Ideally, such systems would facilitate cross-agency data-sharing and enable providers and community organizations to input and access patient- and population-level information.

State- and community-level data-sharing tools could include integrated claims databases that link and share information across payers, service sectors, and provider networks. One example is the Predictive Risk Intelligence System—known as PRISM—a decision-support tool developed by Washington State to support care management for high-risk Medicaid patients. PRISM integrates data from health and social services programs and creates patient risk scores, identifying consumers most in need of care coordination.

States also are supporting on-the-ground integration through two-way electronic referrals between providers and social service organizations. Massachusetts' e-referral system, for example, will connect a subset of community health centers with community resources such as tobacco quit lines, YMCAs, senior centers, and visiting nurse services.

COMMUNITY-LEVEL INTEGRATION EFFORTS

The Oregon Health Authority (OHA) is implementing ***coordinated care organizations*** (CCOs) to assume responsibility for the cost and quality of physical, behavioral, oral, and nontraditional health services. "Innovator agents" coordinate between CCOs and OHA, relaying state-level data to local CCOs and practice-level information about health improvement strategies to OHA.

The ***Camden Coalition of Health Care Providers***, as part of its community-based ACO, engages with representatives from local public health, housing, and transportation agencies to facilitate coordination at both the patient and the community level to better serve high-need patients in Camden, New Jersey.

Maryland has created ***local health improvement coalitions*** to monitor community and population health, identify and respond to hot spots of health needs, and create local plans for health improvement. These coalitions engage a diverse range of stakeholders, including individuals working in housing, education, corrections, and business.

Nemours Health and Prevention Services convenes partners from multiple agencies in Delaware, such as health, education, and child care, to achieve shared children's health goals. Nemours and its partners work to make and sustain policy and practice changes that create healthy environments.

3. Aligned Financing and Payment Methods

Sustaining a meaningful level of health and social services integration requires long-term financing sources and payment models with incentives to encourage ongoing integration.

Financing

The appropriate financing formula will depend on many variables and may shift over time. One option during an initiative's early phases is to apply for grant funding or seek state funds. Maryland helped secure $4 million in the state's 2013 budget for Health Enterprise Zones by projecting a long-term ROI. States also could consider the social impact bond model, in which the state partners with private-sector investors to run small pilots, paying the investors only if the pilot achieves performance targets.

Massachusetts created the Prevention and Wellness Trust Fund, which is allocating almost $60 million over four years to fund competitive, community-level grants for evidence-based prevention activities. Insurer and hospital assessments paid for the fund, which was the first of its kind.[13] Another revenue-raising option is to use a small percentage of insurance premiums, as Vermont currently does to fund health IT efforts. States also could require nonprofit hospitals to allocate a portion of their community benefits spending to population health improvement.[14]

Blended or braided financing—often used in early childhood programs—are strategies for pooling money from different sectors. Blended funding involves commingling funds from different sources into one pot to draw down dollars as needed; costs do not have to be allocated and tracked by funding source. Braided funding coordinates multiple, distinct funding streams to pay for a service package; tracking and accountability for each stream is maintained at the administrative level.

Finally, given that state Medicaid agencies would save money if integrated programs result in improved health, states may examine ways to use these savings to fund nonmedical care. Some states already have been successful at obtaining waivers to use Medicaid dollars to pay for nontraditional health workers, nonmedical services, and local initiatives.[15]

Payment

States could reallocate a portion of social services and public health funding and include a "population health" payment to cover nonmedical services in Medicaid managed care capitation rates. Alternatively, capitation payments could be made directly to a fully integrated multipayer entity that purchases health and nonhealth services for patients.

States also could bundle payments to cover clinical, public health, and social services specific to a population. Payers can draw on lessons from how states used Medicaid funding to cover nonmedical services that address children's needs. For example, Massachusetts Medicaid is running a pediatric asthma bundled payment pilot program that provides nontraditional services and supplies (e.g., mattresses, vacuums, and air conditioners) to mitigate environmental triggers.[16]

States also may consider promoting community- or provider-level budgeting or shared-savings approaches. For example, community health budgets could include a blend of public health, Medicaid, and social services funds. Within those budgets, a population-level shared-savings model could distribute savings to entities that contribute to population health improvements.

IMPLEMENTATION PLANNING FRAMEWORK

With the three core program components in mind, states can develop a strategic plan for integration of health and social services. Five key planning steps include:

Step 1: Establish goals. States can create measurable goals based on their current needs, circumstances, and priorities. They can look to existing resources for insights about the types of goals to pursue (see box: Sources to Inform Program Design). States may consider different goals for different patient populations across a spectrum of complexity.

Step 2: Identify gaps and opportunities. States can determine the types of health and social services integration they wish to pursue by identifying current gaps and opportunities. Local governments and consumer organizations can be

SOURCES TO INFORM PROGRAM DESIGN

- Existing state health improvement plans
- Community health needs assessments and state or communitywide evaluations of the impact of social service, public health, and clinical interventions on health and health care outcomes
- Financial or ROI analysis for statewide or community integration interventions
- The Kaiser Family Foundation's State Health Facts data
- The National Prevention Strategy and Healthy People 2020 goals
- The Institute of Medicine's Community Health Development Process
- Proposals for and assessments of payment, delivery reform, and quality improvement initiatives, including the Centers for Medicare and Medicaid Services' (CMS) Center for Medicare and Medicaid Innovation State Innovation Models Initiative, CMS Health Care Innovation Awards, CMS State Demonstrations to Integrate Care for Dual Eligible Individuals, and the Robert Wood Johnson Foundation's Aligning Forces for Quality and Roadmaps to Health Community Grants

helpful in identifying areas where needs are not being met. In some cases, communities may be resource-rich but ineffective in linking neighborhoods, patients, and providers to resources. States also can identify existing investments that may be reallocated to support integrated care delivery goals.

Step 3: Prioritize opportunities for integration. States can prioritize efforts based on: opportunities that project a positive ROI, existing strengths, and input from stakeholders. Many experts suggest using an asset-based approach to choosing priorities, which takes a community's unique strengths and resources into consideration.[17] Finally, states may consider pursuing a balanced portfolio of short- and long-term interventions and a range of partnering organizations and population targets.[18]

Step 4: Establish an implementation roadmap. An implementation roadmap can guide near- and long-term planning activities and highlight policy considerations. A roadmap would include a developmental stage to pilot new ideas (Phase 1); an expansion stage (Phase 2); and an operational stage (Phase 3) (Exhibit 2).

Exhibit 2. Roadmap for Phased Integration of Health and Social Services: Potential State Activities

	Phase 1 Pilot	Phase 2 Expansion	Phase 3 Fully Operational
Coordination Mechanism	• Fund community-based pilots • Create state-level interagency integration task force	• Choose and staff community entities to lead integration	• Implement statewide community-based integrator agencies
Quality Measurement/ Data-Sharing	• Fund evaluations • Develop new metrics task force	• Test data-sharing and tracking pilots	• Create statewide integrated data exchange
Financing/ Payment	• Provide innovation grants • Test payment demonstrations	• Use simplified financing and payment policies	• Implement performance-based payments and blended financing

Step 5: Create a measurement strategy. A robust measurement strategy will include key metrics that link outcomes and goals and promote accountability. Assessing the ROI for integration also will be an important objective. Although few tools exist to quantify the returns associated with full health and social services integration, states can begin to think about how to identify, assess, and measure these results.[19]

CONCLUSION

While barriers exist for integrating community-based services and health care delivery, states have many policy, financing, and regulatory opportunities available. It is an opportune time for states to work with the federal government, local organizations, and health care professionals to establish meaningful integration of physical and behavioral health, public health, and social services to meet the Medicaid population's complex circumstances and needs.

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Introduction

A promising approach to enhancing the delivery of preventive services in clinical settings is for providers to coordinate, cooperate, and collaborate with community-based organizations to help deliver these services. The Agency for Healthcare Research and Quality (AHRQ) refers to this collaborative approach to the delivery of preventive services as clinical-community relationships. AHRQ has set a long-term goal of understanding whether fostering relationships between clinical practices and community organizations is an effective and feasible way to enhance the delivery of specific clinical preventive services.

The *Clinical-Community Relationships Measures (CCRM) Atlas* is:

- Designed to provide users with a measurement framework and listing of existing measures for clinical-community relationships;
- Intended to help facilitate research, quality improvement projects, and other interventions investigating clinical-community relationships that have been formed for the purposes of improving the delivery of clinical preventive services; and
- Intended to be used by researchers studying clinical-community relationships as well as evaluators of these relationships.

Jumpstart Guide: A Tool to Navigate the *Atlas*

This Jumpstart Guide is a tool to help users navigate the *Clinical Community Relationships Measures Atlas*. By following the listed steps, users will be able to identify existing measures of clinical-community relationships.

To quickly return to the Jumpstart Guide and continue with the next step, click on the Ж symbol. It will appear at the end of each section.

- **Step 1: Gain an Understanding of the Measurement Framework**
  All measures contained within this *Atlas* are organized according to the domains of this framework.

- **Step 2: Review the Measurement Framework Domain Definitions**
  An explanation of each of the domains is provided in the table of domain definitions.

- **Step 3: Examine the CCRM Mapping Table**
  The Master Measure Mapping Table is used to link measures to the framework domains. A quick review of the table will help you during Step 4.

- **Step 4: Follow the Measure Selection Guide**
  This guide will walk you through the steps of identifying the domains pertinent to your interests and identifying relevant measures.

- **Step 5: Review the Profiles of Identified Measures**
  Once you have identified measures that may meet your needs, review the details of measure development, testing, and application.

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1. Why Was the Clinical-Community Relationships Measures Atlas Developed?

Acknowledging the role of prevention in curbing the growing costs of health care and reducing morbidity and mortality in the United States, the 2010 Patient Protection and Affordable Care Act mandates that insurers provide coverage for specific preventive services without imposing cost-sharing requirements (U.S. Congress, 2010). Covered services include[1]:

- Recommendations of the United States Preventive Services Task Force (USPSTF);
- Recommendations of the Advisory Committee On Immunization Practices (ACIP) that have been adopted by the Director of the Centers for Disease Control and Prevention (CDC);
- Guidelines supported by Health Resources and Services Administration's (HRSA's) Bright Futures Project and Uniform Panel of the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children; and
- Recommendations of the Institutes of Medicine (IOM) for HRSA's Women's Preventive Services.

Of particular interest in this project are services that are recommended by the U.S. Preventive Services Task Force (USPSTF) as Grade A and B recommendations (USPSTF, 2010). An "A" or "B" letter grade indicates that the panel recommends a service because there is at least a moderate net benefit for performing the service. The USPSTF recommendations include a broad range of clinical preventive health care services such as screenings, counseling, referrals, and preventive medications. Despite the existence of the USPSTF recommendations, a 2003 study found that patients receive only half of the recommended clinical preventive services overall, and less than 20 percent of recommended counseling or education services (McGlynn et al., 2003). There are many constraints and barriers that can limit delivery of these services in primary care settings, including time constraints, lack of appropriate staffing, and reimbursement issues (Infante et al., 2007). A promising approach to enhancing the delivery of preventive services in clinical settings is for providers to coordinate, cooperate, and collaborate with external nonclinical organizations such as local health departments and community-based organizations that share an interest in improving health and preventing disease and that can deliver these services.

The Agency for Healthcare Research and Quality (AHRQ) refers to this collaborative approach to the delivery of preventive services as clinical-community relationships. AHRQ has set a long-term goal of understanding whether fostering relationships between clinical practices and community organizations is an effective and feasible way to enhance the delivery of specific clinical preventive services. This work is integral to the mission of AHRQ's Prevention and Care Management Portfolio to improve the quality, safety, efficiency, and effectiveness of evidence-

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[1] U.S. Department of Health & Human Services Recommended Preventive Services
http://www.healthcare.gov/law/resources/regulations/prevention/recommendations.html

based preventive and chronic-care management services in primary care settings. AHRQ has funded a series of projects in an effort to better understand and support these relationships.

AHRQ implemented a series of activities from 2008 to 2010 that included:

- Convening a Clinical-Community Linkages Summit in 2008 to encourage collaboration, coordination, and integration among health care clinicians, institutions, and community organizations;
- Conducting a literature review and environmental scan of linkages between clinical practices and community organizations;
- Developing case studies of promising linkages; and
- Convening a 2010 summit of representatives from Federal agencies and other stakeholder organizations to develop a national strategy for promoting linkages to increase the delivery of clinical preventive services.

Stakeholders participating in the 2010 summit identified strategies to support local efforts to develop clinical-community linkages. One key strategy recommended was to develop metrics related to linkages between clinical practices and community organizations. In response, AHRQ launched a research project with the following aim:

- To develop an atlas to help evaluators identify appropriate measures for clinical-community relationships[2] interventions in research studies and demonstration projects, particularly those measures focusing on USPSTF A and B preventive services, which are feasible in community settings.

In developing this *Clinical-Community Relationships Measures Atlas (CCRM Atlas*), we investigated existing clinical-community relationships measurement approaches based on results from a targeted environmental scan and input from expert stakeholders.

The *CCRM Atlas* includes structure, process, and outcome measures related to clinical-community relationships. The measures are organized according to a measurement framework that focuses on the characteristics and activities of clinicians, patients, and community organizations, as well as their interactions and relationships. This framework for describing and organizing the measures reflects the important aspects of establishing and operating clinical-community relationships in practice.

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[2] At the time of the summit, AHRQ referred to clinical-community relationships as clinical-community linkages.

1.1 Purpose

The *CCRM Atlas* aims to support the field of clinical-community relationships measurement by:

- Providing a framework for understanding the measurement of clinical-community relationships;
- Providing a list of existing measures of clinical-community relationships;
- Aligning the existing measures within a clinical-community relationships measurement framework; and
- Providing further details regarding the existing measures, including contextual information such as the preventive service(s) addressed in the setting(s) where the measure was used.

1.2 Intended Audience

The *CCRM Atlas* is designed with the following key audiences in mind:

- Researchers studying clinical-community relationships;
- Evaluators of interventions or demonstration projects that aim to improve clinical-community relationships; and
- Primary care clinicians and community organizations/programs utilizing clinical-community relationships to provide prevention services to patients.

1.3 Scope

The measures within the *CCRM Atlas* focus on the structures, processes, and outcomes that are fundamental to clinical-community relationships. AHRQ's focus on clinical-community relationships seeks to explore how partnerships among primary care settings and community resources are developed, strengthened, and sustained to provide quality preventive care to patients and families. The framework and measures highlighted in the *CCRM Atlas* are based on the following assumptions:

- **The prevention strategy originates in the primary care setting.** The role of a primary care practice encompasses providing for and recognizing the need for preventive health services, including arranging for the delivery of services not provided in the primary care setting (i.e., providing referrals to community resources). Some of the measures listed in the *Atlas* may not have been applied in a primary care setting, but were deemed to be applicable in a primary care setting.

- **There is differentiation between clinics/clinicians and community-based resources.** Primary care clinics/clinicians and community-based resources are defined as separate entities. Some organizations, such as public health departments, may include both clinical and nonclinical resources; however, the aspects of communication and coordination highlighted in the framework are relevant to relationships within these organizations as well.

- **The prevention strategies are focused on counseling and screening services provided in nonclinical community resource settings.** While prevention strategies may vary from practice to practice and community to community, the *Atlas* selected a set of clinical preventive services focused on counseling and screenings that could be provided in community settings. A listing of these services is provided in Appendix A. For example, a family physician could refer a patient to a community-based organization that provides tobacco cessation counseling.

- **Prevention is focused on primary and secondary strategies.** The selected counseling and screening services in the *Atlas* exclude tertiary prevention services such as a clinic's/clinician's referral to a community resource to provide counseling for a patient diagnosed with cancer.

- **Patient health outcome measures are excluded.** The *Atlas* contains measures of the functioning of relationships among clinics/clinicians, patients, and community-based resources. Since evidence exists on patient health outcomes from preventive services delivery and patient health outcome measures are well-defined, patient health outcome measures are not within the scope of this *Atlas*.

- **Measures are accessible.** Only measures that users can access without a fee were included in this *CCRM Atlas*.

1.4 An Emerging Field

The idea of measuring clinical-community relationships is relatively new, and as the field of clinical-community relationships develops, the measurement domains discussed in the *CCRM Atlas* may change; definitions for domains may alter and/or domains may be added or removed. New models for delivering preventive services as well as evolving policies related to health care delivery may affect the applicability or relevance of the domains within the *Atlas*.

Further, there are some domains referenced in this *Atlas* for which no measures currently exist, or the measures that do exist might require additional evidence to establish their effectiveness in evaluating clinical-community relationships. The *Atlas* is being established, in part, to investigate potential measures for evaluating clinical-community relationships. We envision that, as measures for this field are developed and tested, new measures will be added to the *Atlas*.

The framework discussed in the CCRM *Atlas* is intended to be specific enough so that readers can understand the key components of a clinical-community relationship. However, it is also intended to be flexible enough to accommodate this emerging field of study.

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2. What Is a Clinical-Community Relationship?

In the context of this *CCRM Atlas*, a clinical-community relationship exists when a primary care clinician makes a connection with a community resource to provide certain preventive services such as tobacco screening and counseling and, when the clinical practice and the community resource engage in at least one of Himmelman's strategies for working together—networking, coordinating, cooperating, and collaborating (Himmelman, 2002). These strategies are distinguished by the formality of the relationships, key characteristics (e.g., time commitments, levels of trust, access to resources), and levels of resource sharing.

2.1 Examples of Clinical-Community Relationships

The AHRQ Health Care Innovations Exchange contains several examples of clinical-community relationships. These examples, while varying by the community resources used, the communities served, and the preventive services provided, all demonstrate effective use of clinical-community relationships as a strategy for the provision of preventive services.

Example 1: In Richmond, Virginia, a group of medical practices incorporated a system called Electronic Linkage System (eLinkS) into its daily workflow (AHRQ, 2008a). eLinkS prompted clinicians to offer behavior counseling and then referred patients to community resources to help provide those services. The community resources provided services such as group counseling for alcohol and smoking behavior as well as telephone counseling for weight loss. Another component of this clinical-community relationship was a community resource's ability to update patient records through a Web site that automatically sent information regarding a patient's progress back to the patient's clinician. This clinical-community relationship resulted in a high rate of referrals for counseling services as well as improved behaviors such as high quit rates among smokers.

Example 2: The Community Health Educator Referral Liaisons (CHERL) project in Michigan used liaisons, also known as health navigators, to help reduce patients' risky health behaviors (e.g., drinking, smoking, physical inactivity) (AHRQ, 2008c). After receiving the referral from a clinician, the CHERL provided ongoing counseling to the patient and referred the patient to appropriate community resources. The CHERL updated clinicians on the patients' goals and intervention plans as well as patients' progress in meeting goals. Patients who participated in the program reported better diets, more physical activity, and less smoking and drinking.

Example 3: The King County Steps to Health project used community health workers as liaisons among clinic/clinicians, patients, and community resources (AHRQ, 2008b). The clinical-community relationships formed in this project fostered referrals to community resources for various health promotion services. The project provided evidence of patients' improved healthy behaviors such as increased physical activity, and better outcomes for asthma and diabetes patients.

2.2 Difference Between Care Coordination and Clinical-Community Relationships

There is a distinction between care coordination and clinical-community relationships as defined here. The Agency for Healthcare Research and Quality's *Care Coordination Measures Atlas* defines care coordination as, "the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the appropriate delivery of health services" (McDonald et al., 2010, p. 4). Organizing care involves the marshaling of personnel and other resources needed to carry out all required patient care activities and is often managed by the exchange of information among participants responsible for different aspects of care. Clinical-community relationships would fit under this definition of care coordination. However, most activities typically measured under "care coordination" are between groups commonly thought of as health care organizations. Care coordination is often employed to address the needs of a specific population of patients including those with multiple co-morbidities and consumers of high levels of health resources. Measuring care coordination is essential in improving the quality of primary care services. **The *CCRM Atlas* focuses on a subset of care coordination between clinics and community-based resources that are not typically considered health care organizations.**

2.3 The Role of Public Health in Clinical-Community Relationships

AHRQ recognizes that the specific activities and collaborative relationships involving local public health departments vary depending on the needs of local delivery systems. In some localities the public health department may fill the role of the primary care clinic or clinician as we have defined it, in other localities it may fill the role of a community resource (e.g., providing services in a nonclinical setting), and in some places it may serve in both roles. In any of these situations, the measurement framework for clinical-community relationships presented in this *Atlas* still applies as the elements of communication highlighted in the framework are still needed. This is equally true whether the relationship is between a public health primary care site and a private community resource, a private primary care site and a public health community resource, or a public health primary care site and a public health community resource. Even in this third situation it is important to measure and track the structure and functioning of the relationship to ensure that it is meeting the needs of the community for delivery of the relevant clinical preventive services. This *CCRM Atlas* is intended to provide a common framework to help understand and evaluate clinical-community relationships.

3. What Is the Clinical-Community Relationships Measurement Framework?

This chapter contains:

- An overview of the Clinical-Community Relationships Measurement (CCRM) Framework;
- An explanation of the larger context within which the framework exists; and
- A description of the foundation and contents of the framework.

3.1 Overview of the Measurement Framework

The Measurement Framework is a conceptual framework for the *Atlas* that provides a structure for identifying, categorizing, and understanding the basic components of effective relationships between primary care practices and community resources for providing certain clinical preventive services. The framework is organized around a series of measurement domains that can provide the basis for empirical assessments of the structures, processes, and outcomes of the relationship at the practice or community level.

The theoretical basis for the measurement framework presented is twofold. The Etz bridging model (Etz et al., 2008) and Donabedian's structure-process-outcome model (Donabedian, 1980) provide the foundation of the measurement framework.

Etz's bridging model describes a set of characteristics on the clinic/clinician side of the "bridge" that influences the ability to initiate connections to community resources, and a set of characteristics on the community resource side that facilitates connections to primary care practices. These attributes can be considered foundational anchors that must be established on each side of the bridge for a clinical-community relationship to be developed. The measurement framework expands on this model to take explicit account of the patient role and relationship with both the clinic/clinician and the community resource sides of the bridge. **The patient, clinic/clinician, and community resource *elements* and the *relationships* among these elements form one dimension of the measurement framework.** A more detailed explanation of this bridging model is given in Section 3.3.1.

For the purpose of examining clinical-community relationships, Donabedian's structure-process-outcome model has been applied as the second dimension used to categorize measurement domains within the measurement framework. This approach allows measures of structure, process, and outcome to be considered and examined for the clinic/clinician, patient, and community resource elements and for the relationships between these three elements.

Table 3-1 presents the measurement domains within the clinical-community relationships measurement framework. Brief definitions of the measurement domains are listed below in Table 3-2.

Conceptual Framework Domains and Definitions (Table 3-2);
Master Measurement Table (Table 4-1)

Table 3-1. Clinical-Community Relationships Measures Framework

Categories of measurement domains	**Measurement Domains**					
	Elements			**Relationships**		
	Clinic/clinician	**Patient**	**Community resource**	**Clinic/clinician-patient**	**Clinic/clinician-community resource**	**Patient-community resource**
Structure Domains	• Information technology infrastructure • Service capacity • Accessibility • Training • Delivery system design • Organizational infrastructure	• Information technology infrastructure • Capacity for self-management • Ability to access primary care • Ability to access the community resource • Health literacy	• Information technology infrastructure • Service capacity • Accessibility • Training • Delivery system design • Organizational infrastructure	• Proactive and ready • clinician • Informed and activated patient	• Nature and strength of the inter-organizational relationship	• Proactive and ready community resource • Informed and activated patient
Process Domains	• Readiness for behavior change • Outreach to obtain knowledge of and familiarity with community resources	• Readiness for behavior change • Outreach to obtain knowledge of and familiarity with community resources	• Readiness for behavior change • Marketing of services	• Referral process • Assessment and goal setting • Self-management support • Shared decision making	• Referral • process • Feedback and communication • Timeliness	• Referral process • Assessment and goal setting • Self-management support • Communication and follow through/follow-up
Outcome Domains	• Stage of behavior change • Knowledge of and familiarity with community resources	• Stage of behavior • change • Knowledge of and familiarity with community resources	• Stage of behavior change • Marketing results	• Patient experience • Cost/efficiency • Delivery of service • Patient-centeredness	• Clinician experience • Community resource experience • Cost/efficiency	• Patient experience • Cost/efficiency • Delivery of service • Patient-centeredness

Notes:
The table presents measurement domains within the CCRM Framework
The elements (clinic/clinician, patient, and community resource) and the relationships among these elements form one dimension of the measurement framework.
Refer to Section 3.3.1 for more information.
Donabedian's structure-process-outcome model is the second dimension used to categorize measurement domains.

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CCRM Framework (Table 3-1)
Master Measurement Table (Table 4-1)

Table 3-2. Definitions of Measurement Domains

Domain	Definition
Ability to access primary care	The degree to which a patient has or perceives that he/she has the ability to access primary care services
Ability to access the community resource	The degree to which a patient has or perceives that he/she has the ability to access the community resource
Accessibility	The degree to which the attributes of the clinic/clinician or the community resource affect how accessible its services are (e.g., open scheduling and open hours)
Assessment and goal setting	The degree of interaction between a clinic/clinician or referred community resource and a patient to develop a plan of action for preventive services
Capacity for self-management	The degree of environmental support that a patient has for his/her health management, which could include family, community, psychological, and social support
Clinician experience	The level of utility from a clinic/clinician's perspective of participation in the clinical-community resource relationship
Communication and follow through/followup	The level of interaction between a community-based resource and patient after the initial connection between them
Community resource experience	The level of utility from a community resource's perspective of participation in the clinical-community resource relationship
Cost/efficiency	The amount of resources, time, energy, and productivity associated with the provision of the services and activities connected with the relationship
Delivery of service	The rate of completion or receipt of services
Delivery system design	The scope of professional services provided and how those services are provided by a clinic/clinician and/or community resource (i.e., this domain contains measures of the presence or degree to which certain professional services exist as well as measures of the methods of providing such services)
Feedback and communication	The level and means of communication between the community resource and the clinic/clinician
Health literacy	The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions
Information technology infrastructure	The degree of availability and use of relevant aspects of information technology within a clinic/clinician organization, patient, or community resource
Informed and activated patient	The level of trust and increase in level of information a patient has (or is perceived to have) for participating in a relationship
Knowledge of and familiarity with community resources	The clinician's and/or patient's degree of awareness of the availability, range of services, level of cultural competency, and quality of services provided by various community resources
Marketing of services	The level of action and effort taken by a community resource to share information with clinics/clinicians and patients about the availability and types of preventive services provided
Marketing results	The results of marketing activities that a community resource could be engaging in
Nature and strength of the inter-organizational relationship	The level of intensity of a relationship between a clinic/clinician and community resource (based on Himmelman's definitions of networking, coordinating, cooperating, and collaborating). This includes the degree to which the relationship can overcome common barriers of working together— time, trust, and turf (Himmelman, 2002).

CCRM Framework (Table 3-1)
Master Measurement Table (Table 4-1)

Table 3-2. Definitions of measurement domains (continued)

Domain	Definition
Organizational infrastructure	The way in which a clinic/clinician and/or community resource organizes the people and office process components of its business; the degree to which it is supported by a sustainable business model and governance structure (i.e., this domain contains measures of the presence or degree to which such organizational infrastructure exists)
Outreach to obtain knowledge of and familiarity with community resources	The level of action and effort taken by a clinic/clinician to learn about the availability of community resources and the services provided
Patient-centeredness	The degree to which attributes of whole-person care, family-centered care, respectfulness, cultural sensitivity, and advocacy for a patient exist
Patient experience	The level of utility from a patient’s perspective of participation in the clinician-patient or patient-community resource relationship
Proactive and ready clinician	The level of involvement a clinician provides in a clinical-patient relationship
Proactive and ready community resource	The level of involvement a community-based resource provides in a patient-community resource relationship
Readiness for behavior change	The level and/or type of activity that a clinic/clinician, patient, or community resource engages in to prepare for behavioral change that might be affected by a referral to a community resource
Referral process	Data (e.g., frequency) related to the process of developing, obtaining, and confirming a referral among all of the relationships
Self-management support	The level of interaction between the clinician and the patient aimed at helping patients stay informed about recommended clinical preventive services, and overcoming any barriers to the receipt of services that would prevent them from being active participants in their own care
Service capacity	The level of capacity, including amount of staff, resources, etc. that a clinic/clinician and/or community resource has to provide preventive services as well as manage the relationship(s)
Shared decision making	The level of clinician-patient information sharing regarding the preventive health services being addressed and the level of patient expression of his or her preferences and values
Stage of behavior change	The level, movement, or degree of sustainability achieved by a clinic/clinician, patient, and/or community resource among the various stages of readiness for behavioral change (i.e., pre-contemplation, contemplation, preparation, action, and maintenance)
Timeliness	The amount of time it takes for clinical preventive services to be delivered when clinicians make referrals to community resources
Training	The level of education and/or competency of individuals within a clinic/clinician and/or community resource to provide preventive services

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3.2 The Context of the Measurement Framework

We recognize that the core elements of the framework—the clinic/clinician, the patient, and the community resource—exist within a broader context that includes many other influential factors.

The effects of each of the framework's elements and the interactions between them should be understood within this broader context. However, there was no attempt to include all aspects of the broader policy environment in the framework, nor is the framework a comprehensive model for the entirety of primary care. Rather, it is a way to understand, assess, and improve the functioning of an approach to the delivery of preventive services that is consistent with the direction of national policy and strategy, and is likely to be responsive to the needs of patients.

We recognize that preventive health screenings may occur in a large variety of settings including faith-based organizations, supermarkets, senior centers, and others that do not involve a referral from a primary care clinician. This *Clinical-Community Relationships Measures Atlas* represents the first phase of a multi-phase endeavor. While we acknowledge the need for measures of different types of clinical-community relationships, our focus in this first phase is on measures of clinical-community relationships for the delivery of certain preventive services where the referral to the community service is initiated in the primary care setting.

Because each community is unique, the utility and relevance of the measure domains that fall into the three elements of the framework may differ from community to community. Communities differ in population size, wealth, educational attainment, cultural diversity, the challenges they face, and their approach to addressing those challenges. The specific health and community resources available and accessible in each community are unique and may logically influence the relationships between the clinic/clinician and patient elements.

The patient element exists within a broader socioecological model, as illustrated in Figure 3-1. Individual characteristics of patients, the influence of their family structure, the control of work space and organizational environments, and broader community policies all have an effect on the individual patient.

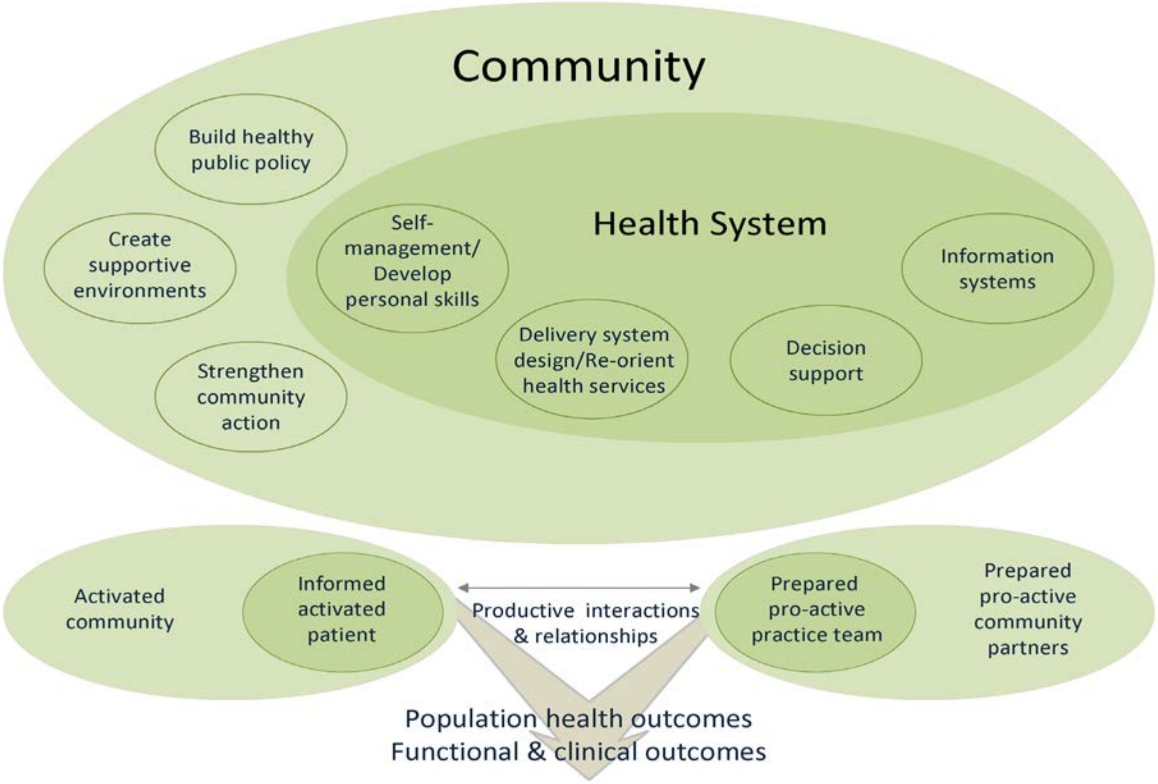
Figure 3-1. Socioecological model

Division of Cancer Prevention and Control, National Center for Chronic Disease Prevention and Health Promotion. (2011). Social Ecological Model. Retrieved September 21, 2012. From http://www.cdc.gov/cancer/crccp/sem.htm.

Providing a broader context for the clinic/clinician element, the Expanded Chronic Care Model (Barr et al., 2003) depicted in Figure 3-2 recognizes that patient-centered interaction is not limited to the one-on-one encounter in the exam room. The clinician is supported by a team of health professionals whose roles are diverse. Some provide care management or care coordination; some serve as boundary spanners between various resources; and some help patients navigate the complexity of the health system. In Example 2, from Section 2.1, clinicians engaged the assistance of Community Health Educator Referral Liaisons (CHERLs) to help manage their clients and orchestrate their clients' preventive services.

The model for clinical-community relationships illustrated in Figure 3-3 can be thought of as a way of re-conceptualizing the interactions between the components of the system labeled *informed activated patient*, *prepared pro-active practice team*, and *prepared pro-active community partners* in Figure 3-2.

Figure 3-2. Expanded chronic care model



Barr, V. J., Robinson, S., Marin-Link, B., et al. (2003). The Expanded Chronic Care Model: Integrating Population Health Promotion. Retrieved September 21, 2012. From http://www.longwoods.com/content/16763.

In sum, the measurement framework is an attempt to provide an overall description of the factors that may influence clinical-community relationships for the purpose of providing certain clinical preventive services. As noted above, the particular characteristics that may influence clinical-community relationships vary from community to community. For this reason, the elements of the framework that are relevant or useful, and the measures that arise from the framework, would be expected to vary accordingly. This framework should not be construed as a checklist to be completed the same way in every patient or every primary care practice, but rather as a guide for clarifying the specific category or categories of measures that are relevant in particular circumstances.

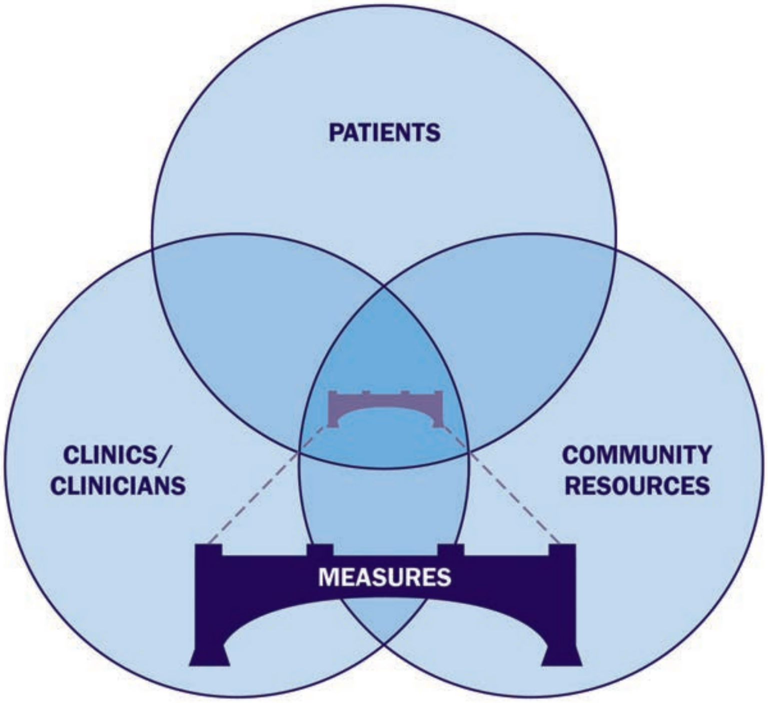
3.3 The Foundation of the Measurement Framework

This section describes the foundation of the measurement framework that is presented in Table 3-1. The theoretical work that supports the framework is further discussed, as well as the rationale for how different types of measures are conceptualized and organized in the framework.

3.3.1 Expanded Bridging Model

Figure 3-3 depicts the foundation of the framework. The three interconnected circles in the Venn diagram represent the three principal elements of the framework—the patient, the primary care clinic/clinician, and the community resource. The *patient element* is defined as the individual who receives primary care services, including preventive care and illness care; this definition includes family members and/or others directly responsible for the care of the individual. The *clinic/clinician element* includes individual clinicians and clinic support staff operating in clinical settings in which primary care is delivered. The *community resource element* encompasses a range of organizations and programs that provide services to patients.

Figure 3-3. Foundation of the measurement framework for clinical-community relationships



Imposed over the diagram is the Etz bridge (Etz et al., 2008), which connects the clinic/clinician and the community resource. According to Etz et al., the concept of a bridge "suggests a dynamic and interactive connection as well as the need for strong foundations, for knowledge of local landscapes, and for continuous maintenance" (2008, p. S391). Etz's bridging model describes a set of characteristics on the clinic/clinician side that influence the ability to initiate connections to community resources, and a set of characteristics on the community resource side that facilitate connections to primary care practices. These attributes can be considered as foundational anchors that must be established at each side of the bridge for a clinical-community relationship to be developed. Anchoring characteristics on the clinic/clinician side include the capacity to assess patient risk, ability to provide brief counseling, capacity and ability to refer, and awareness of community resources. Anchoring characteristics on the community resource side include the availability, accessibility, affordability, and perceived value of services provided by the community resource. The factors that allow or facilitate development of structural anchors on both sides of the bridge represent measurement domains in the clinical-community relationship measurement framework. The existence, prevalence, and strength of these factors are potential measures that can be mapped to the measurement domains.

Establishing a bridge between primary care clinics/clinicians and community resources can be accomplished without involving the patient element. Etz's bridging model does not factor in patient measures; therefore, the larger bridge in Figure 3-3 does not extend to the intersection that includes the patient element. Nevertheless, this measurement framework expands on this model to take explicit account of the patient role and relationship with both the clinic/clinician and the community resource.

Figure 3-3 also contains a "shadow bridge" that connects all three elements. This shadow bridge has been inserted to suggest the possibility that this framework may evolve to include measure domains that capture measures of the relationship of the triad, if warranted by further research.

3.3.2 Types of Measurement Domains

Donabedian's structure-process-outcome model provides a seminal framework for examining health services and patient outcomes (Donabedian, 1980). According to Donabedian, *structure* refers to the physical and organizational properties of a setting in which care is provided; *process* is the treatment or service being provided to a patient; and *outcomes* are results of the treatment or service.

For the purpose of examining clinical-community relationships, the structure-process-outcome model has been expanded beyond the context of health services and applied to patients and community resources, so that it provides a means to categorize measurement domains along one dimension of the measurement framework presented in Table 3-1. This allows the examination of how specific factors intrinsic to primary care clinics/clinicians, patients, and community resources may contribute to an overall understanding of the effectiveness of clinical-community relationships.

Measures of structure, process, and outcome may be considered and examined at six different points in Figure 3-3, which include: the clinic/clinician, patient, and community resource elements in themselves; the three intersections representing the interaction between the patient and clinic/clinician; the patient and the community resource; and the clinic/clinician and community resource.

The following three examples illustrate how **structure domains** may manifest within the measurement framework:

- A primary care clinic with a robust information technology infrastructure may be well equipped to make electronic referrals to community-based organizations. Measures of such an infrastructure would be placed within the *information technology infrastructure* domain.

- A community-based organization that employs allied health professionals—mental health specialists, alcohol and drug counselors, or lactation coaches—may have an increased capacity to deliver specific recommended preventive services. Measures of these capacities would be placed within the *service capacity* domain.

- A patient who does not have a convenient way of traveling to a community resource or whose work hours overlap with the hours that the community resource is open may be less likely to use that community resource. Measures of the existence or prevalence of such barriers would be placed within the *ability to access the community resource* domain.

The **process** domains in the framework relate to care planning and referrals. Process factors in this context may also be broadened to include any activity or service that would facilitate providing preventive services by a community resource. Examples of these activities include:

- Work that a clinic or clinician might undertake to obtain knowledge of existing community resources. Measures of these actions would be placed within the *outreach to obtain knowledge and familiarity with community resources* domain.

- From the community resource perspective, marketing activities to promote clinic/clinician and patient awareness of services offered. Measures of these activities would be placed within the m*arketing of services* domain.

Outcome domains relate to the patient's receipt of services and clinician and patient experiences of care as shown in Table 3-1. An outcome can be construed as the *result* of any activity or process germane to this context. While domains related to patient health outcomes are beyond the scope for this effort, other outcomes resulting from activities or processes engaged in by any element within the framework may be within scope. Examples of these results include:

- After collaborating with a community organization to provide preventive services, a physician may have more office time and see more patients in his/her work week. Measures of these types of results would be placed within the *cost/efficiency* domain.

- A patient received behavioral counseling by visiting a community organization he/she was referred to. Measures of the patient's rate of completion for these counseling services would be placed with the *delivery of service* domain.

3.4 Contents of the Measurement Framework

Table 3-1 above presents the Clinical-Community Relationships Measurement Framework. The contents of the table represent measurement domains, or broad conceptual or functional areas that can be used to categorize specific measures.

Measurement domains in the table are organized along two dimensions. Within columns, domains are organized according to the three principal elements—the clinic/clinician, patient, and community resource—and the relationships between those elements—clinic/clinician-patient, clinic/clinician-community resource, and patient-community resource. Within rows, domains are organized according to the categories of measures that fall under each domain—structure, process, and outcome. It should be noted that several measurement domains can be used to categorize measures in multiple elements. For example, *organizational infrastructure* is a structure domain that applies to both the clinic/clinician element and the community resource element.

3.4.1 Elements of the Measurement Framework

Each element in the framework—patient, community resource, and clinic/clinician—possesses intrinsic characteristics and factors that may be important candidate measurement domains in an overall framework for examining the functioning and effectiveness of clinical-community relationships.

The Clinic/Clinician Element

This element encompasses two entities—the primary care clinic and the individual primary care clinician. For the purpose of this framework, the primary care clinic/clinician element serves as the initiation point for clinical-community relationships (i.e., where referrals for preventive services originate). In the CHERL program, (Example 2, Section 2.1), the clinicians and the CHERL are both within the clinic/clinician element. Measures of the existence of liaisons would be contained within the *delivery system design* domain.

The Patient Element

The patient is the subject of a referral and there are factors specific to a patient outside of the patient's relationship with either the clinician or the community resource that may affect whether or not a clinician's referral to a community resource has the desired result. One such structural factor was mentioned above—namely, the patient's ability to access the community resource.

The Community Resource Element

The community resource element encompasses a range of organizations and programs that provide services to patients, including USPSTF-recommended clinical preventive services. A community resource needs to maintain staffing and other resources to provide its range of services and programs. Measures of these structural factors would fall within the *service capacity* domain.

3.4.2 Relationships Among Elements of the Measurement Framework

Each element does not operate in isolation. The interactions between the elements, depicted by the intersections of the overlapping circles in Figure 3-3, are also essential domains of measurement for understanding clinical-community relationships for prevention.

The Clinic/Clinician-Patient Relationship

The interaction between the clinic/clinician and patient plays an important role in evaluating clinical-community relationships. There must be a level of trust between the clinician and the patient for the clinical-community relationship to work. These parties must be cognizant of each other's expectations, needs and situation; the better the communication between the clinician and patient, the more likely a clinical-community relationship will be effective. Measures of the level of trust a patient has in this relationship would be included within the *Informed and activated* *patient* domain. A way to measure the clinician's level of involvement in the relationship would be found within the *Proactive and ready clinician* domain.

The Clinic/Clinician-Community Resource Relationship

The clinical-community relationship is at the center of the measurement framework and builds on the concept of the Etz bridge. To create a linkage or relationship, two organizations must be aware of each other, find some common benefit that can be derived from the connection, and then establish routine systems of maintaining that connection in a manner that produces a positive cost-benefit ratio or increased perceived value. To the extent that communication and coordination between organizations appears to be seamless from the patient's perspective, there will likely be more effective service delivery.

Well-functioning clinical-community relationships also can help each organization achieve its mission, both financially and operationally. Having well-defined relationships and roles for service delivery can improve organizational efficiency and sustainability, along with staff development, motivation, and improved job satisfaction. In the eLinkS program, (Example 1, Section 2.1), there was a level of trust between the medical practices and community resources, which enabled both parties to share and update the patient's records. Measures of these levels of trust would be found within the *nature and strength of the inter-organizational relationship* domain.

The Patient-Community Resource Relationship

Similar to the clinic/clinician-patient relationship, the interaction between the patient and the community resource plays an important role in evaluating clinical-community relationships. The level of patient trust in a relationship with a community resource and the community resource's ability to engage the patient can affect the community resource's success in providing appropriate preventive services. Such measures would be found by specifying this relationship as the relationship of interest (as opposed to the clinic/clinician-patient relationship) and then looking within the *informed and activated patient* and *proactive and ready community resource* domains respectively.

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4. How Do Existing Measures of Clinical-Community Relationships Align with the Measurement Framework?

This chapter contains:

- An overview of how existing measures for clinical-community relationships are organized within the measurement framework described in Chapter 3;
- A table of existing measures mapped to the measurement framework; and
- An explanation of how to use the table (Table 4-1) to identify measures of clinical-community relationships.

4.1 Measure Mapping Table

To classify the clinical-community relationship measures according to the two dimensions of the measurement framework, a Measure Mapping Table was developed that displays the intersection of clinical-community relationship measurement domains (listed vertically) and the elements or relationships that would be the focus of each measure (listed horizontally). Measures were indexed, or "mapped," according to the measure domain into which they fall in order to indicate which aspect of clinical-community relationships the measure is assessing.

The measures contained in the *CCRM Atlas* were identified during an environmental scan that was conducted in 2011 to identify existing measures of linkages between clinical practices and community organizations. Appendix C provides further details regarding the environmental scan and how the information for each measure was extracted.

Each existing measure identified to be relevant to clinical-community relationships has a profile that provides details regarding the measure. Exhibit 4-1 provides a listing and explanation of the information collected for measures. The profiles for each measure are in Chapter 5. Relevant information for each section of the profile was obtained and extracted from publications identified through the environmental scan of clinical-community relationship measures mentioned above. It should be noted that when measures that focused on mental health settings were determined to be adaptable for primary care settings, these measures were included in the *CCRM Atlas*.

As noted previously, the field of clinical-community relationships is in its infancy as are the measures that assess these relationships. Many measures included in the *CCRM Atlas* are from selected sections of survey instruments. Users are cautioned that even though individual items from surveys are mapped to particular domains, most instruments should be used in their entirety. Typically, measure testing is conducted on the entire measure; performance of measurement based on individual items is usually unknown. Further research, such as psychometric and validity testing may need to be conducted on these measures in a clinical-community relationship setting. It may be possible to seek advice directly from a measure developer about any potential adaptations.

Exhibit 4-1. Measurement profile template

Number of the measure in the *Atlas* and the title of measure as described by the measure developer

Domain	The domain the measure belongs to	**Element/ relationship**	The element/relationship the measure belongs to
Instrument	For those measure that apply, the instrument from which the measure is derived		
Purpose	The intent of the measure		
Format/data source	Identifies how the measure data were collected. The data sources are based on the National Quality Measures Clearinghouse (AHRQ, 2011) full listing of data sources. Appendix B provides a listing and description of the data sources.		
Measure type	Identifies whether the measure is a structure, process, or outcome measure	**Date**	The date the measure was originally developed/released/or published
Preventive service/ USPSTF	Provides the listing of the preventive service(s) that the measure has previously addressed, including USPSTF recommendations (USPSTF, 2010)		
Clinical practice	Identifies the primary care setting where the measure was applied. These include physical and/or clinical settings where clinicians and support staff deliver primary care, including family medicine, internal medicine, pediatrics, and obstetrics and gynecology. Clinicians include licensed physicians, doctors of osteopathy, nurse practitioners, registered nurses, nurse midwives, or physician assistants who provide primary care services.		
Denominator	Describes the lower part of the fraction used to calculate a rate or ratio defining the total population of interest for a measure		
Numerator	Describes the upper part of the fraction used to calculate a rate or ratio defining the subset of the population of interest that meets a measure's criterion		
Development & testing	A summary of relevant information concerning the development of the measure, as well as reliability and validity testing applied to the measure. Measure developers were contacted to seek updated testing information.		
Past or validated application	Describes the settings and target populations to which the measure was applied. This includes the type of clinical practice to which the measure was applied.		
Citation(s)	List of relevant sources for the measure, and its development or testing		
Notes	Contains any additional relevant information		

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4.2 Master Measure Mapping Table

Each existing measure of clinical-community relationships was mapped to a domain in the measurement framework. The Master Measure Mapping Table (see Table 4-1) presents the existing measures that align to clinical-community relationship domains and the element(s) or relationship(s) that the measure assesses. A shaded cell for a domain in a particular row indicates that the domain does not apply to the element or relationship in the corresponding column. A non-shaded cell for a domain in a particular row indicates that the domain does apply to the element or relationship in the corresponding column. A blank non-shaded cell indicates that no measures currently exist for the domain.

The numbers in parentheses indicate the total existing measures for a specific domain and element/relationship. For example, there are three identified measures for the *clinician experience* domain to assess the clinic/clinician-community resource relationship. The measure numbers following the parentheses correspond to the number assigned to each measure on Table 5-1, the List of Measures. Hence, the following three measures are under the *clinician experience* domain to assess the clinic/clinician-community resource relationship:

- #9 - Physician satisfaction with service coordination (Alzheimer's Service Coordination Program [ASCP] Physician Survey)
- #11 - Whether or not a clinician would refer any family caregiver to intervention in the future (ASCP Physician Survey); and
- # 21 - The effectiveness of communication between practice and community resource (GP-CLI Interview).

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CCRM Framework (Table 3-1)
Conceptual Framework Domains and Definitions (Table 3-2)

Table 4-1. Master Measure Mapping Table ***(Table is divided into two pages.)***

	Element/Relationship					
Domain	**Clinic/clinician**	**Patient**	**Community resource**	**Clinic/clinician – patient**	**Clinic/clinician – community resource**	**Patient – community resource**
Ability to access primary care	▨		▨	▨	▨	▨
Ability to access community resource	▨	**(1)** 3	▨	▨	▨	▨
Accessibility		▨		▨	▨	▨
Assessment and goal setting	▨	▨	▨	**(1)** 13	▨	
Capacity for self-management	▨		▨	▨	▨	▨
Clinician experience	▨	▨	▨	▨	**(3)** 9. 11, 21	▨
Communication and follow through/follow-up	▨	▨	▨	▨	▨	
Community resource experience	▨	▨	▨	▨		▨
Cost/efficiency	▨	▨	▨			
Delivery of service	▨	▨	▨		▨	
Delivery system design		▨		▨	▨	▨
Feedback and communication	▨	▨	▨	▨	**(2)** 12, 20	▨
Health literacy	▨		▨	▨	▨	▨
Information technology infrastructure				▨	▨	▨
Informed and activated patient	▨	▨	▨	**(1)** 5	▨	
Knowledge of and familiarity with community resources	**(2)** 10, 22		▨	▨	▨	▨
Marketing of services	▨	▨		▨	▨	▨

Notes:
A shaded cell indicates that the domain does not apply to the element or relationship.
A non-shaded cell indicates that the domain does apply to the element or relationship.
A blank non-shaded cell indicates that no measures currently exist for the domain.
The numbers in parentheses indicate the total existing measures for a specific domain and element/relationship.
The measure names can be found in Table 5-1

CCRM Framework (Table 3-1)
Conceptual Framework Domains and Definitions (Table 3-2)

Table 4-1. Master Measure Mapping Table (continued)

Domain	Element/Relationship					
	Clinic/clinician	**Patient**	**Community resource**	**Clinic/clinician – patient**	**Clinic/clinician – community resource**	**Patient – community resource**
Marketing results	▨	▨		▨	▨	▨
Nature and strength of the inter-organizational relationship	▨	▨	▨	▨		▨
Organizational infrastructure		▨		▨	▨	▨
Outreach to obtain knowledge of and familiarity with community resources			▨	▨	▨	▨
Patient-centeredness	▨	▨	▨		▨	
Patient experience	▨	▨	▨		▨	
Proactive and ready clinician	▨	▨	▨	**(2)** **6**, **7**	▨	▨
Proactive and ready community resource	▨	▨	▨	▨	▨	
Readiness for behavior change		**(2)** **2**, **18**		▨	▨	▨
Referral process	▨	▨	▨	**(7)** **1**, **4**, **8**, **14**, **15**, **17**, **19**, **21**		**(1)** **16**
Self-management support	▨	▨	▨		▨	
Service capacity		▨		▨	▨	▨
Shared decision making	▨	▨	▨		▨	▨
Stage of behavior change				▨	▨	▨
Timeliness	▨	▨	▨	▨		▨
Training		▨		▨	▨	▨

Notes:
A shaded cell indicates that the domain does not apply to the element or relationship.
A non-shaded cell indicates that the domain does apply to the element or relationship.
A blank non-shaded cell indicates that no measures currently exist for the domain.
The numbers in parentheses indicate the total existing measures for a specific domain and element/relationship.
The measure names can be found in Table 5-1.

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CCRM Framework (Table 3-1)
Conceptual Framework Domains and Definitions (Table 3-2)
Master Measurement Table (Table 4-1)

4.3 How to Select a Measure – The Measure Selection Guide

This section is intended to help users identify existing clinical-community relationship measures that can help evaluate their clinical-community relationship interventions, demonstration projects, or other research initiatives.

Two key steps are involved in finding a measure to meet your evaluation needs:

1. Identify the measures relevant to your intervention; and
2. Review the relevant measure profiles.

Identifying the measures relevant to your intervention involves the steps outlined below:

a. Specify the element(s) or relationship(s) of interest (i.e., choose a column in Table 4-1);

b. Specify the domains of a clinical-community relationship that are of interest (i.e., choose a row in Table 4-1); and

c. Go to the intersection of the column you selected in step (a) and the row you chose in step (b) to identify the relevant measures.

Once you have identified the relevant measures, go to the Measure Profiles in Chapter 5 to examine the relevant measures in more detail and determine whether they meet your evaluation needs.

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4.3.1 An Example of How to Use the Guide

More detailed guidance for implementing the above steps is provided below.

1. **Identify the measures relevant to your intervention.**

Example: [3]

Dr. X is developing a 6-month program to improve awareness of sexually transmitted infections (STIs) among his patients. Dr. X is going to refer patients to one of three available community centers that provide STI and sexual health counseling. Dr. X will use a brief questionnaire during his consultations with patients to prescreen those eligible for a referral as

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[3] This example is a quality improvement activity and it is assumed that the clinician explicitly obtained the patients' approval to share/receive information with the community resources.

well as assess the patient's level of readiness for behavior change. Those patients who agree to participate in the program will be given a prescription for counseling, which serves as a referral form for free counseling at any of the three community centers. The community centers agreed to maintain a list of all clients who came for STI and sexual health counseling at the respective sites as well as who completed the counseling. At the end of the program, the community centers will supply Dr. X with the listing of clients who came at least once and a list of those who actually completed their services.

Dr. X is interested in understanding the following:

- *Is there any correlation between the patient's level of readiness for behavior change and the patient's acting on the referral?*
- *Will the prescription for free counseling result in more patients using the counseling services? Dr. X tried verbal referrals a year ago with a similar group of patients; most patients from that group did not use the counseling services.*

a. *Specify the element(s) or relationship(s) of interest*

A single intervention may involve multiple elements or relationships as units of analysis in an evaluation of the intervention. Hence, it is important that you first identify which element(s) and/or relationship(s) you are interested in. Questions to consider include: Who is the intervention primarily targeted toward? Who will carry out the intervention?

The intervention in the above example is targeted toward patients. The community centers will be helping to carry out the intervention by supplying Dr. X with the listing of clients who (1) used the services (i.e., came at least once) and who (2) completed the services. Hence the element and relationship that are of interest here are:

- Element: patient; and
- Relationship: patient – community resource.

b. *Specify the domains of a clinical-community relationship that are of interest*

A single intervention may employ multiple mechanisms whose effect you may want to measure. Therefore, you will want to map each one to a measurement domain.

Using the example listed above, Dr. X is interested in the effect of the patient's readiness for change and the prescription for a free referral on the rate of confirmed referrals and the rate of delivery of services. Hence, the measurement domains of interest are:

CCRM Framework (Table 3-1)
Conceptual Framework Domains and Definitions (Table 3-2)
Master Measurement Table (Table 4-1)

- Readiness for behavior change (patient element);[4]
- Referral process (patient-community relationship element); and
- Delivery of service (patient-community relationship element).

Each domain is listed on the relevant rows of the Master Measure Mapping Table (Table 4-1).

c. *Identify relevant clinical-community relationship measures.*

Using the element(s) and/or relationship(s) you identified in step "a" and the domain(s) you identified from step "b", locate the relevant clinical-community relationships measures on the Master Measure Mapping Table by finding where they intersect.

For example, if you are looking for a measure of patient's readiness for behavior change, scan down the Patient Element column until you reach the row with *readiness for behavior change*. The box that represents the intersection of this column and row lists the existing measure(s) in the *CCRM Atlas* that evaluate a patient's readiness for behavior change - measures 2 and 18.

Similarly, if you are interested in evaluating the prescription for counseling effect on the patient's rate of confirming the referral by contacting the community service, look at the measure(s) in the *referral process* domain of the patient-community resource relationship: Measure 16. Since you might also be interested in the effect of either the prescription or the patient's readiness for change on actual completion of counseling services, look at the measure(s) in the *delivery of service* domain of the patient-community resource relationship: there currently aren't any measures within this domain indicating the need for measure development and testing.

2. Review relevant measure profiles.

Once you have identified the measures you need to evaluate your intervention, go to the Measure Profiles in Chapter 5 to obtain more information about each measure. This information should be used to guide the selection of specific measures for use in evaluating the intervention.

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[4] Several measurement domains can be used to categorize measures that apply to multiple elements/relationships.

CCRM Framework (Table 3-1)
Conceptual Framework Domains and Definitions (Table 3-2)
Master Measurement Table (Table 4-1)

5. What Are the Existing Measures of Clinical-Community Relationships?

This chapter presents specific measure mapping tables with profiles for each measure. Each individual measure has a measure profile designed to provide more detailed information on the measure's purpose, format and data source, validation and testing, applications, and key sources. Table 5-1 below provides an index to the measure numbers (left column) cited in the Master Measure Mapping Table (Table 4-1) and the order in which the individual measure mapping tables with profiles appear in this chapter.

Table 5-1. List of measures

#	Measure name
1	Patient recall of referral to local agencies (Safety Check Parental/Guardian Post-Visit Survey)
2	Parental interest in following up on the local agency referral (Safety Check Parental/Guardian Post-Visit Survey)
3	Parental confidence in being able to use a local agency referral (Safety Check Parental/Guardian Post-Visit Survey)
4	Clinician recall of referral to a local agency (Safety Check Practitioner Post-Visit Survey)
5	Clinician perception of parent interest in referral (Safety Check Practitioner Post-Visit Survey)
6	Clinician confidence in ability to instruct patient/family in proper use of local agency referral (Safety Check Practitioner Post-Visit Survey)
7	Information about area (community) resources is offered by clinician (Wrap-Around Observation Form-2)
8	Plan of care includes at least one public and/or private community service/resource (Wrap-Around Observation Form-2)
9	Physician satisfaction with service coordination (Alzheimer's Service Coordination Program [ASCP] Physician Survey)
10	Changes in clinicians' knowledge of available services in the local community (ASCP Physician Survey)
11	Whether or not a clinician would refer any family caregiver to intervention in the future (ASCP Physician Survey)
12	Clinician receipt of treatment plan from the service coordinator (ASCP Physician Survey)
13	Clinician discussion of treatment plan with patients or family caregivers (ASCP Physician Survey)
14	Patients referred to a community health educator referral liaison (CHERL)
15	Patient engagement with CHERL
16	CHERL referrals to community resources
17	Referral rate for intensive counseling from a community program
18	Rate of patients that were ready to improve a targeted behavior
19	Connection to resource (Continuity of Care Practices Survey – Practice Level [CCPS-P])
20	Coordination of care (CCPS-P)
21	The effectiveness of communication between practice and community resource (GP-LI)
22	The quality of the service provided by community resource to a practice (GP-LI)

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CCRM Framework (Table 3-1)
Conceptual Framework Domains and Definitions (Table 3-2)
Master Measurement Table (Table 4-1)

Exhibit 5-1. Measure 1: Patient recall of referral to local agencies (Safety Check Parental/Guardian Post-Visit Survey)

Domain:	Referral process	**Element/ relationship:**	Clinic/clinician-patient
Instrument:	Safety Check Parental/Guardian Post-Visit Survey		
Purpose:	Clinicians in the *Pediatric Research in Office Settings* program were trained on providing violence prevention related community referrals. This measure tracks patient recall of referrals to local agencies.		
Format/data source:	Patient/Individual Survey		
Measure type:	Process	**Date:**	2006
Preventive service/ USPSTF:	Other–Mental Health*		
Clinical practice:	Primary care–Pediatrics		
Denominator:	Number of respondents to parent/guardian post-visit survey (Q2)		
Numerator:	Number of respondents who selected “Yes” to local agency referral (Q2d)		
Development & testing:			
Past or validated application:			
Citation(s):	Barkin, S., Ip, E. H., Finch, S., et al. Clinician practice patterns: linking to community resources for childhood aggression. *Clinical Pediatrics* (2006) 45:750-756.		
Notes:	Please be aware that this measure is using only a selected section of an entire survey instrument. Therefore, this individual measure may need to undergo further reliability and validation testing to ensure that it can be applied in a clinical-community relationship setting.		

* This is a measure that was originally applied in a mental health setting, but it could be adapted for a primary care setting.

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CCRM Framework (Table 3-1)
Conceptual Framework Domains and Definitions (Table 3-2)
Master Measurement Table (Table 4-1)

Exhibit 5-2. Measure 2: Parental interest in following up on the local agency referral (Safety Check Parental/Guardian Post-Visit Survey)

Domain:	Readiness for behavior change	**Element/ relationship:**	Patient
Instrument:	Safety Check Parental/Guardian Post-Visit Survey		
Purpose:	Clinicians in the *Pediatric Research in Office Settings* program were trained on providing violence prevention-related community referrals. This measures the parent's level of interest in following up on the local agency referral.		
Format/data source:	Patient/Individual Survey		
Measure type:	Process	**Date:**	2006
Preventive service/ USPSTF:	Other–Mental Health*		
Clinical practice:	Primary care–Pediatrics		
Denominator:	Number of respondents to parent/guardian post-visit survey (Q3)		
Numerator:	Number of respondents who selected "Interested" or "Very interested" in following up on the local agency referral (Q3d)		
Development & testing:			
Past or validated application:			
Citation(s):	Barkin, S., Ip, E. H., Finch, S., et al. Clinician practice patterns: linking to community resources for childhood aggression. *Clinical Pediatrics* (2006) 45:750-756.		
Notes:	Please be aware that this measure is using only a selected section of an entire survey instrument. Therefore, this individual measure may need to undergo further reliability and validation testing to ensure that it can be applied in a clinical-community relationship setting.		

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CCRM Framework (Table 3-1)
Conceptual Framework Domains and Definitions (Table 3-2)
Master Measurement Table (Table 4-1)

Exhibit 5-3. Measure 3: Parental confidence in being able to use a local agency referral (Safety Check Parental/Guardian Post-Visit Survey)

Domain:	Ability to access the community resource	**Element/ relationship:**	Patient
Instrument:	Safety Check Parental/Guardian Post-Visit Survey		
Purpose:	Clinicians in the *Pediatric Research in Office Settings* program were trained on providing violence prevention related community referrals. This measures the parents' confidence that they will be able to use the local agency referral.		
Format/data source:	Patient/Individual Survey		
Measure type:	Structural	**Date:**	2006
Preventive service/ USPSTF:	Other–Mental Health*		
Clinical practice:	Primary care–Pediatrics		
Denominator:	Number of respondents to parent/guardian post-visit survey (Q4)		
Numerator:	Number of respondents who selected "Confident" or "Very confident" in following up on the local agency referral (Q4d)		
Development & testing:			
Past or validated application:			
Citation(s):	Barkin, S., Ip, E. H., Finch, S., et al. Clinician practice patterns: linking to community resources for childhood aggression. *Clinical Pediatrics* (2006) 45:750-756.		
Notes:	Please be aware that this measure is using only a selected section of an entire survey instrument. Therefore, this individual measure may need to undergo further reliability and validation testing to ensure that it can be applied in a clinical-community relationship setting.		

* This is a measure that was originally applied in a mental health setting, but it could be adapted for a primary care setting.

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CCRM Framework (Table 3-1)
Conceptual Framework Domains and Definitions (Table 3-2)
Master Measurement Table (Table 4-1)

Exhibit 5-4. Measure 4: Clinician recall of referral to a local agency (Safety Check Practitioner Post-Visit Survey)

Domain:	Referral process	**Element/ relationship:**	Clinic/clinician-patient
Instrument:	Safety Check Practitioner Post-Visit Survey		
Purpose:	Clinicians in the *Pediatric Research in Office Settings* program were trained on providing violence prevention-related community referrals. This measure tracks the clinicians' recall of referrals to local agencies.		
Format/data source:	Health professional survey		
Measure type:	Process	**Date:**	2006
Preventive service/ USPSTF:	Other–Mental Health*		
Clinical practice:	Primary care–Pediatrics		
Denominator:	Number of respondents to practitioner post-visit survey (Q4)		
Numerator:	Number of respondents who selected "Yes" to Local Agency Resource (Q4d)		
Development & testing:			
Past or validated application:			
Citation(s):	Barkin, S., Ip, E. H., Finch, S, et al. Clinician practice patterns: linking to community resources for childhood aggression. *Clinical Pediatrics* (2006) 45:750-756.		
Notes:	Please be aware that this measure is using only a selected section of an entire survey instrument. Therefore, this individual measure may need to undergo further reliability and validation testing to ensure that it can be applied in a clinical-community relationship setting.		

* This is a measure that was originally applied in a mental health setting, but it could be adapted for a primary care setting.

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CCRM Framework (Table 3-1)
Conceptual Framework Domains and Definitions (Table 3-2)
Master Measurement Table (Table 4-1)

Exhibit 5-5. Measure 5: Clinician perception of parent interest in referral (Safety Check Practitioner Post-Visit Survey)

Domain:	Informed and activated patient	**Element/ relationship:**	Clinic/clinician-patient
Instrument:	Safety Check Practitioner Post-Visit Survey		
Purpose:	Clinicians in the *Pediatric Research in Office Settings* program were trained on providing violence prevention-related community referrals. This measures the clinicians' perception of their patient's interest in the local agency referral.		
Format/data source:	Health professional survey		
Measure type:	Structural	**Date:**	2006
Preventive service/ USPSTF:	Other–Mental Health*		
Clinical practice:	Primary care–Pediatrics		
Denominator:	Number of respondents to practitioner post-visit survey (Q5)		
Numerator:	Number of respondents who selected "Interested" or "Very interested" in following up on the local agency referral (Q5d)		
Development & testing:			
Past or validated application:			
Citation(s):	Barkin, S., Ip, E. H., Finch, S., et al. Clinician practice patterns: linking to community resources for childhood aggression. *Clinical Pediatrics* (2006) 45:750-756.		
Notes:	Please be aware that this measure is using only a selected section of an entire survey instrument. Therefore, this individual measure may need to undergo further reliability and validation testing to ensure that it can be applied in a clinical-community relationship setting.		

* This is a measure that was originally applied in a mental health setting, but it could be adapted for a primary care setting.

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CCRM Framework (Table 3-1)
Conceptual Framework Domains and Definitions (Table 3-2)
Master Measurement Table (Table 4-1)

Exhibit 5-6. Measure 6: Clinician confidence in ability to instruct patient/family in proper use of local agency referral (Safety Check Practitioner Post-Visit Survey)

Domain:	Proactive and ready clinician	**Element/ relationship:**	Clinic/clinician-patient
Instrument:	Safety Check Practitioner Post-Visit Survey		
Purpose:	Clinicians in the *Pediatric Research in Office Settings* program were trained on providing violence prevention related community referrals. This measures the clinicians’ level of confidence in instructing the patient/family in the proper use of a local agency referral.		
Format/data source:	Health professional survey		
Measure type:	Process	**Date:**	2006
Preventive service/ USPSTF:	Other–Mental Health*		
Clinical practice:	Primary care–Pediatrics		
Denominator:	Number of respondents to practitioner post visit survey (Q6)		
Numerator:	Number of respondents who selected “Confident” or “Very confident” in ability to instruct this patient-family in the proper use of a local agency referral (Q6d)		
Development & testing:			
Past or validated application:			
Citation(s):	Barkin, S., Ip, E. H., Finch, S., et al. Clinician practice patterns: linking to community resources for childhood aggression. *Clinical Pediatrics* (2006) 45:750-756.		
Notes:	Please be aware that this measure is using only a selected section of an entire survey instrument. Therefore, this individual measure may need to undergo further reliability and validation testing to ensure that it can be applied in a clinical-community relationship setting.		

* This is a measure that was originally applied in a mental health setting, but it could be adapted for a primary care setting.

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CCRM Framework (Table 3-1)
Conceptual Framework Domains and Definitions (Table 3-2)
Master Measurement Table (Table 4-1)

Exhibit 5-7. Measure 7: Information about area (community) resources is offered by clinician (Wrap-Around Observation Form-2)

Domain:	Proactive and ready clinician	**Element/relationship:**	Clinic/clinician-patient
Instrument:	Wrap-Around Observation Manual – Second Version		
Purpose:	For families involved in a care team receiving wrap-around services, the question assesses whether information about resource interventions in the area is offered to the team.		
Format/data source:	External audit. Question 1 of the 48-item Wrap-Around Observation Form-2, which elicits information from a trained observer on whether a team mentions at least one specific resource/intervention (e.g., A.A, vocational rehab, Teammates) to the parent or asks if the parent is involved or needs community resources/intervention.		
Measure type:	Structural	**Date:**	2003
Preventive service/ USPSTF:	Other–Mental Health*		
Clinical practice:	Other		
Denominator:	Number of patients or families eligible for wraparound services and form filled by observer. (Question 1)		
Numerator:	Number of “yes” responses noted by observer during family meeting with care coordinator. “Yes” if the team mentions or asks if the parent is involved in resources/interventions. “Yes” if the team asks about or mentions resources/interventions and the parent is already involved or does not show an interest in such services, and thus the team does not provide contact information. (Question 1)		
Development & testing:	Reliability of the WOF-2 was assessed during 30 family planning meetings with 26 different families during a 24-month period. Data were collected by eight graduate students and one research assistant who served as observers at the family planning meetings. To assess reliability at each meeting, two observers went to the meeting to collect data using the WOF-2.		
Past or validated application:	Those in Lancaster County, Nebraska, who participated in an evaluation designed to examine the impact of a system of care for children with serious emotional disturbance and their families.		
Citation(s):	Nordness, P. D. and Epstein, M. H. Reliability of the Wraparound Observation Form—Second Version: an instrument designed to assess the fidelity of the Wraparound approach. *Mental Health Services Research* (2003) 5(2):89-96. Epstein, M. H., Nordness, P. D., Kutash, K., et al. Assessing the Wraparound process during family planning meetings. *Journal of Behavioral Health Services & Research* (2003) 30:352-362.		
Notes:	Please be aware that this measure is using only a selected section of an entire survey instrument. Therefore, this individual measure may need to undergo further reliability and validation testing to ensure that it can be applied in a clinical-community relationship setting.		

* This is a measure that was originally applied in a mental health setting, but it could be adapted for a primary care setting.

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CCRM Framework (Table 3-1)
Conceptual Framework Domains and Definitions (Table 3-2)
Master Measurement Table (Table 4-1)

Exhibit 5-8. Measure 8: Plan of care includes at least one public and/or private community service/resource (Wrap-Around Observation Form-2)

Domain:	Referral process	**Element/ relationship:**	Clinic/clinician-patient
Instrument:	Wrap-Around Observation Manual – Second Version		
Purpose:	For families involved in a care team receiving wrap-around services, the question assesses if information about resource interventions in the area is offered to the team.		
Format/data source:	External audit. Question 2 of the 48-item Wrap-Around Observation Form-2, which elicits information from a trained observer of whether a team specifically identifies at least one public (e.g., Health and Human Services, Lincoln Public Schools, Social Security Income) and/or private (e.g., private therapists/counselors, drug rehab centers) community service/resource in the plan of care.		
Measure type:	Process	**Date:**	2003
Preventive service/ USPSTF:	Other–Mental Health*		
Clinical practice:	Other		
Denominator:	Number of patients or families eligible for wraparound services and form filled by observer. (Question 1)		
Numerator:	Number of "yes" responses noted by observer during family meeting with care coordinator. "Yes" only if one public and/or private service is included in the plan. These agencies must be accessible from the client's community. (Question 1)		
Development & testing:	Reliability of the WOF-2 was assessed during 30 family planning meetings with 26 different families during a 24-month period. Data were collected by eight graduate students and one research assistant who served as observers at the family planning meetings. To assess reliability at each meeting, two observers went to the meeting to collect data using the WOF-2.		
Past or validated application:	Those in Lancaster County, Nebraska, who participated in an evaluation designed to examine the impact of a system of care for children with serious emotional disturbance and their families.		
Citation(s):	Nordness, P. D. and Epstein, M. H. Reliability of the Wraparound Observation Form—Second Version: An instrument designed to assess the fidelity of the Wraparound Approach. *Mental Health Services Research* (2003) 5(2):89-96. Epstein, M. H., Nordness, P. D., Kutash, K., et al. Assessing the wraparound process during family planning meetings. *Journal of Behavioral Health Services & Research* (2003) 30:352-362.		
Notes:	Please be aware that this measure is using only a selected section of an entire survey instrument. Therefore, this individual measure may need to undergo further reliability and validation testing to ensure that it can be applied in a clinical-community relationship setting.		

* This is a measure that was originally applied in a mental health setting, but it could be adapted for a primary care setting.

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CCRM Framework (Table 3-1)
Conceptual Framework Domains and Definitions (Table 3-2)
Master Measurement Table (Table 4-1)

Exhibit 5-9. Measure 9: Physician satisfaction with service coordination (Alzheimer's Service Coordination Program [ASCP] Physician Survey)

Domain:	Clinician experience	**Element/ relationship:**	Clinic/clinician-community resource
Instrument:	Alzheimer's Service Coordination Program (ASCP) Physician Survey		
Purpose:	Questionnaire asked clinician's satisfaction with the Alzheimer's Service Coordination Program - the program was a care partnership arrangement linking primary care physicians with a community organization that specializes in dementia education and support.		
Format/data source:	Health professional survey		
Measure type:	Outcome	**Date:**	1997
Preventive service/ USPSTF:	Other–Mental Health*		
Clinical practice:	Primary Care - Family Practice; Primary Care - Internal Medicine		
Denominator:	Clinicians in the area who have at least six dementia patients and who referred family caregivers diagnosed with dementia to a service coordinator and responded to question (Q10)		
Numerator:	Number of clinicians responding "Very Satisfied" or "Satisfied"		
Development & testing:	Tested versions of the survey with academic general internists for clarity and brevity before the instrument was fielded.		
Past or validated application:			
Citation(s):	Fortinsky, R. H., Unson, C. G., and Garcia, R. I. Helping family caregivers by linking primary care physicians with community-based dementia care services: The Alzheimer's Service Coordination Program. *Dementia: The International Journal of Social Research and Practice* (2002) 1(2), 227-240.		
Notes:	Please be aware that this measure is using only a selected section of an entire survey instrument. Therefore, this individual measure may need to undergo further reliability and validation testing to ensure that it can be applied in a clinical-community relationship setting.		

* This is a measure that was originally applied in a mental health setting, but it could be adapted for a primary care setting.

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CCRM Framework (Table 3-1)
Conceptual Framework Domains and Definitions (Table 3-2)
Master Measurement Table (Table 4-1)

Exhibit 5-10. Measure 10: Changes in clinicians’ knowledge of available services in the local community (ASCP Physician Survey)

Domain:	Knowledge and familiarity with community resource	**Element/relationship:**	Clinic/clinician
Instrument:	Alzheimer’s Service Coordination Program (ASCP) Physician Survey		
Purpose:	Physicians are asked whether their knowledge of community resources available to their patients with dementia and these patients’ families increased, remained unchanged, or decreased compared with before their participation in the Alzheimer’s Service Coordination Program.		
Format/data source:	Health professional survey		
Measure type:	Outcome	**Date:**	1997
Preventive service/ USPSTF:	Other–Mental Health*		
Clinical practice:	Primary Care - Family Practice; Primary Care - Internal Medicine		
Denominator:	Clinicians in the area who have at least six dementia patients and who referred family caregivers diagnosed with dementia to a service coordinator and responded to question (Q7)		
Numerator:	Number of clinicians responding “Yes”		
Development & testing:	Tested versions of the survey with academic general internists for clarity and brevity before the instrument was fielded.		
Past or validated application:			
Citation(s):	Fortinsky, R. H., Unson, C. G., and Garcia, R. I. Helping family caregivers by linking primary care physicians with community-based dementia care services: The Alzheimer’s Service Coordination Program. *Dementia: The International Journal of Social Research and Practice* (2002) 1(2), 227-240.		
Notes:	Please be aware that this measure is using only a selected section of an entire survey instrument. Therefore, this individual measure may need to undergo further reliability and validation testing to ensure that it can be applied in a clinical-community relationship setting.		

* This is a measure that was originally applied in a mental health setting, but it could be adapted for a primary care setting.

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CCRM Framework (Table 3-1)
Conceptual Framework Domains and Definitions (Table 3-2)
Master Measurement Table (Table 4-1)

Exhibit 5-11. Measure 11: Whether or not a clinician would refer any family caregiver to intervention in the future (ASCP Physician Survey)

Domain:	Clinician experience	**Element/ relationship:**	Clinic/clinician-community resource
Instrument:	Alzheimer's Service Coordination Program (ASCP) Physician Survey		
Purpose:	Physicians are asked whether they would refer their patients to the Alzheimer's Service Coordination Program after participating in the program.		
Format/data source:	Health professional survey		
Measure type:	Outcome	**Date:**	1997
Preventive service/ USPSTF:	Other–Mental Health*		
Clinical practice:	Primary Care - Family Practice; Primary Care - Internal Medicine		
Denominator:	Clinicians in the area who have at least six dementia patients and who referred family caregivers diagnosed with dementia to a service coordinator and responded to question (Q9)		
Numerator:	Number of clinicians responding "Yes"		
Development & testing:	Tested versions of the survey with academic general internists for clarity and brevity before the instrument was fielded.		
Past or validated application:			
Citation(s):	Fortinsky, R. H., Unson, C. G., and Garcia, R. I. Helping family caregivers by linking primary care physicians with community-based dementia care services: The Alzheimer's Service Coordination Program. *Dementia: The International Journal of Social Research and Practice* (2002) 1(2), 227-240.		
Notes:	Please be aware that this measure is using only a selected section of an entire survey instrument. Therefore, this individual measure may need to undergo further reliability and validation testing to ensure that it can be applied in a clinical-community relationship setting.		

* This is a measure that was originally applied in a mental health setting, but it could be adapted for a primary care setting.

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CCRM Framework (Table 3-1)
Conceptual Framework Domains and Definitions (Table 3-2)
Master Measurement Table (Table 4-1)

Exhibit 5-12. Measure 12: Clinician receipt of treatment plan from the service coordinator (ASCP Physician Survey)

Domain:	Feedback and communication	**Element/ relationship:**	Clinic/clinician-community resource
Instrument:	Alzheimer's Service Coordination Program (ASCP) Physician Survey		
Purpose:	Physicians are asked whether they received a service plan from the ASCP Service Coordinator while participating in the program.		
Format/data source:	Health professional survey		
Measure type:	Process	**Date:**	1997
Preventive service/ USPSTF:	Other - Mental Health*		
Clinical practice:	Primary Care - Family Practice; Primary Care - Internal Medicine		
Denominator:	Clinicians in the area who have at least six dementia patients and who referred family caregivers diagnosed with dementia to a service coordinator and responded to question (Q1)		
Numerator:	Number of clinicians responding "Yes" (a or b)		
Development & testing:	Tested versions of the survey with academic general internists for clarity and brevity before the instrument was fielded.		
Past or validated application:			
Citation(s):	Fortinsky, R. H., Unson, C. G., and Garcia, R. I. Helping family caregivers by linking primary care physicians with community-based dementia care services: The Alzheimer's Service Coordination Program." *Dementia: The International Journal of Social Research and Practice* (2002) 1(2), 227-240.		
Notes:	Please be aware that this measure is using only a selected section of an entire survey instrument. Therefore, this individual measure may need to undergo further reliability and validation testing to ensure that it can be applied in a clinical-community relationship setting.		

* This is a measure that was originally applied in a mental health setting, but it could be adapted for a primary care setting.

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CCRM Framework (Table 3-1)
Conceptual Framework Domains and Definitions (Table 3-2)
Master Measurement Table (Table 4-1)

Exhibit 5-13. Measure 13: Clinician discussion of treatment plan with patients or family caregivers (ASCP Physician Survey)

Domain:	Assessment and goal setting	**Element/ relationship:**	Clinic/clinician-patient
Instrument:	Alzheimer’s Service Coordination Program (ASCP) Physician Survey		
Purpose:	Physicians are asked whether they reviewed or discussed treatment plan with patients or family caregivers while participating in the program.		
Format/data source:	Health professional survey		
Measure type:	Process	**Date:**	1997
Preventive service/ USPSTF:	Other - Mental Health*		
Clinical practice:	Primary Care - Family Practice; Primary Care - Internal Medicine		
Denominator:	Clinicians in the area who have at least six dementia patients and who referred family caregivers diagnosed with dementia to a service coordinator and responded to question (Q2). Must have answered “Yes” (a or b) to (Q1) as well.		
Numerator:	Number of clinicians responding “Yes”		
Development & testing:	Tested versions of the survey with academic general internists for clarity and brevity before the instrument was fielded.		
Past or validated application:			
Citation(s):	Fortinsky, R. H., Unson, C. G., and Garcia, R. I. Helping family caregivers by linking primary care physicians with community-based dementia care services: The Alzheimer’s Service Coordination Program. *Dementia: The International Journal of Social Research and Practice* (2002) 1(2), 227-240.		
Notes:	Please be aware that this measure is using only a selected section of an entire survey instrument. Therefore, this individual measure may need to undergo further reliability and validation testing to ensure that it can be applied in a clinical-community relationship setting.		

* This is a measure that was originally applied in a mental health setting, but it could be adapted for a primary care setting.

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CCRM Framework (Table 3-1)
Conceptual Framework Domains and Definitions (Table 3-2)
Master Measurement Table (Table 4-1)

Exhibit 5-14. Measure 14: Patients referred to a community health educator referral liaison (CHERL)

Domain:	Referral process	**Element/ relationship:**	Clinic/clinician-patient
Instrument:	N/A		
Purpose:	This measure calculates the proportion of eligible patients who received referrals to a CHERL by a clinician if the patient was identified by the clinician as needing improvement in one or more of the four unhealthy behaviors.		
Format/data source:	Electronic health/medical record. A computerized support system was developed to collect patient data; track patient calls, dates of service, and clinician feedback; and guide the counseling. Patient-specific health behavior and demographic information was entered by the CHERL based on self-report by the patients.		
Measure type:	Process	**Date:**	2006
Preventive service/ USPSTF:	Alcohol Misuse Counseling; Healthy Diet Counseling; Obesity Screening and Counseling – Adults; Tobacco Use Counseling and Interventions - Non-Pregnant		
Clinical practice:	Primary Care - Family Practice; Primary Care - Internal Medicine		
Denominator:	Number of eligible patients (those identified by the clinician as needing improvement in one or more unhealthy behaviors): Patients eligible for improvement were those who had smoked one puff or more in the past 7 days; had drunk two alcoholic drinks per one occasion most days in the past month; did not eat a low-fat diet or at least five total fruits and/or vegetables per day; and/or did not participate in moderate exercise at least 5 days per week, or vigorously at least 3 days per week.		
Numerator:	This was an accounting of the number of faxes received for each CHERL (the practices faxed referrals to the CHERL)		
Development & testing:	The Reach, Efficacy/Effectiveness, Adoption, Implementation, Maintenance (RE-AIM) model provided the framework for the analysis of study results.		
Past or validated application:	Adult patients at fifteen practices selected for convenience in three Michigan communities were eligible for CHERL referral if a patient was identified by the clinician as needing improvement in one or more of the four unhealthy behaviors.		
Citation(s):	Holtrop JS, Dosh SA, Torres T, Thum YM. The community health educator referral liaison (CHERL): A primary care practice role for promoting healthy behaviors. *American Journal of Preventive Medicine* (2008) 35:S365-S372.		
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CCRM Framework (Table 3-1)
Conceptual Framework Domains and Definitions (Table 3-2)
Master Measurement Table (Table 4-1)

Exhibit 5-15. Measure 15: Patient engagement with CHERL

Domain:	Referral process	**Element/ relationship:**	Clinic/clinician-patient
Instrument:	N/A		
Purpose:	This measure calculates the proportion of eligible patients who received referrals to a CHERL by a clinician if the patient was identified by the clinician as needing improvement in one or more of the four unhealthy behaviors.		
Format/data source:	Electronic health/medical record. A computerized support system was developed to collect patient data; track patient calls, dates of service, and clinician feedback; and guide the counseling. Patient-specific health behavior and demographic information was entered by the CHERL based on self-report by the patients.		
Measure type:	Process	**Date:**	2006
Preventive service/ USPSTF:	Alcohol Misuse Counseling; Healthy Diet Counseling; Obesity Screening and Counseling – Adults; Tobacco Use Counseling and Interventions - Non-Pregnant		
Clinical practice:	Primary Care - Family Practice; Primary Care - Internal Medicine		
Denominator:	Number of eligible patients (those identified by the clinician as needing improvement in one or more unhealthy behaviors): Patients eligible for improvement were those who had smoked one puff or more in past 7 days; had drunk two alcoholic drinks per one occasion most days in the past month; did not eat a low-fat diet or at least five total fruits and/or vegetables per day; and/or did not participate in moderate exercise at least 5 days per week, or vigorously at least 3 days per week.		
Numerator:	This was a count of the number of patients who had at least one “visit” with a CHERL (visits were by phone).		
Development & testing:	The Reach, Efficacy/Effectiveness, Adoption, Implementation, Maintenance (RE-AIM) model provided the framework for the analysis of study results.		
Past or validated application:	Adult patients at 15 practices selected for convenience in three Michigan communities were eligible for CHERL referral if a patient was identified by the clinician as needing improvement in one or more of the four unhealthy behaviors.		
Citation(s):	Holtrop, J. S., Dosh, S. A., Torres, T., Thum, Y. M. The community health educator referral liaison (CHERL): A primary care practice role for promoting healthy behaviors. *American Journal of Preventive Medicine* (2008) 35:S365-S372.		
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CCRM Framework (Table 3-1)
Conceptual Framework Domains and Definitions (Table 3-2)
Master Measurement Table (Table 4-1)

Exhibit 5-16. Measure 16: CHERL referrals to community resources

Domain:	Referral process	**Element/ relationship:**	Patient-community resource
Instrument:	N/A		
Purpose:	This measure calculates the proportion of patients working with a CHERL who were referred to at least one community resource that provided assistance with one or more of the four unhealthy behaviors.		
Format/data source:	Electronic health/medical record. A computerized support system was developed to collect patient data; track patient calls, dates of service, and clinician feedback; and guide the counseling. Patient-specific health behavior and demographic information was entered by the CHERL based on self-report by the patients.		
Measure type:	Process	**Date:**	2006
Preventive service/ USPSTF:	Alcohol Misuse Counseling; Healthy Diet Counseling; Obesity Screening and Counseling – Adults; Tobacco Use Counseling and Interventions - Non-Pregnant		
Clinical practice:	Primary Care - Family Practice; Primary Care - Internal Medicine		
Denominator:	Number of eligible patients (those identified by the clinician as needing improvement in one or more unhealthy behavior): Patients eligible for improvement were those who had smoked one puff or more in past 7 days; had drunk two alcoholic drinks per one occasion most days in the past month; did not eat a low-fat diet or at least five total fruits and/or vegetables per day; and/or did not participate in moderate exercise at least 5 days per week, or vigorously at least 3 days per week. The patient must have completed a baseline call with the CHERL.		
Numerator:	The number of clients who received at least one referral from the CHERL to a community resource.		
Development & testing:	The Reach, Efficacy/Effectiveness, Adoption, Implementation, Maintenance (RE-AIM) model provided the framework for the analysis of study results.		
Past or validated application:	Adult patients at 15 practices selected for convenience in three Michigan communities were eligible for CHERL referral if a patient was identified by the clinician as needing improvement in one or more of the four unhealthy behaviors.		
Citation(s):	Holtrop, J. S., Dosh, S. A., Torres, T., Thum, Y. M. The community health educator referral liaison (CHERL): A primary care practice role for promoting healthy behaviors. *American Journal of Preventive Medicine* (2008) 35:S365-S372.		
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CCRM Framework (Table 3-1)
Conceptual Framework Domains and Definitions (Table 3-2)
Master Measurement Table (Table 4-1)

Exhibit 5-17. Measure 17: Referral rate for intensive counseling from a community program

Domain:	Referral process	**Element/ relationship:**	Clinic/clinician-patient
Instrument:	N/A		
Purpose:	An electronic linkage system (eLinkS) tracked the promotion of health behavior counseling and automation of patient referrals to community counseling services. This measure calculated the proportion of all patients with risk factors referred for intensive counseling.		
Format/data source:	Electronic health/medical record. Utilizing the electronic medical record as a platform, eLinkS was designed to (1) help clinicians systematically perform elements of the 5A's that are feasible in busy practice settings (i.e., asking about health behaviors, offering brief advice, and agreeing on next steps); (2) make it fast and easy to refer patients to intensive counseling outside the office; and (3) establish bidirectional communication between practices and community counselors.		
Measure type:	Process	**Date:**	2008
Preventive service/ USPSTF:	Alcohol Misuse Counseling; Healthy Diet Counseling; Obesity Screening and Counseling – Adults; Tobacco Use Counseling and Interventions - Non-Pregnant		
Clinical practice:	Primary Care - Family Practice; Primary Care - Internal Medicine		
Denominator:	Patients who reported they wanted to address an unhealthy behavior and engaged to address the unhealthy behavior (A1-A3)		
Numerator:	Number of patients referred to intensive counseling (A4)		
Development & testing:	Prompts of the eLinkS were applied to the 5A's of health behaviors.		
Past or validated application:	Nine primary care practices in the Tidewater region of Virginia were recruited. The practices, members of a single medical group and of the Virginia Ambulatory Care Outcomes Research Network (ACORN), share a common type of EMR (GE Centricity Physician Office©) that is managed by a central informatics staff. The practices have used the EMR for 3 to 10 years. Practice size ranged from 1 to 30 clinicians (median = 3), and 48 (87%) clinicians participated in the study. Two sites were solo practices, five had three clinicians, one had eight clinicians, and one (a family medicine residency program) had 30 part-time clinicians and residents.		
Citation(s):	Krist, A. H., Woolf, S. H., Frazier, C. O., et al. An electronic linkage system for health behavior counseling effect on delivery of the 5A's. *American Journal of Preventive Medicine* (2008) 35:S350-S358.		
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CCRM Framework (Table 3-1)
Conceptual Framework Domains and Definitions (Table 3-2)
Master Measurement Table (Table 4-1)

Exhibit 5-18. Measure 18: Rate of patients that were ready to improve a targeted behavior

Domain:	Readiness for behavior change	**Element/ relationship:**	Patient
Instrument:	N/A		
Purpose:	An electronic linkage system (eLinkS) tracked the promotion of health behavior counseling and automation of patient referrals to community counseling services. This measure calculated the proportion of all patients who were engaged to address an unhealthy behavior.		
Format/data source:	Electronic health/medical record. Utilizing the electronic medical record (EMR) as a platform, eLinkS was designed to (1) help clinicians systematically perform elements of the 5A's that are feasible in busy practice settings (i.e., asking about health behaviors, offering brief advice, and agreeing on next steps); (2) make it fast and easy to refer patients to intensive counseling outside the office; and (3) establish bidirectional communication between practices and community counselors.		
Measure type:	Process	**Date:**	2008
Preventive service/ USPSTF:	Alcohol Misuse Counseling; Healthy Diet Counseling; Obesity Screening and Counseling – Adults; Tobacco Use Counseling and Interventions - Non-Pregnant		
Clinical practice:	Primary Care - Family Practice; Primary Care - Internal Medicine		
Denominator:	Patients who reported an unhealthy behavior and were advised by clinician to change their behavior (A1-A2)		
Numerator:	Number of patients engaged to modify their behavior (A3)		
Development & testing:	Prompts of the eLinkS were applied to the 5A's of health behaviors.		
Past or validated application:	Nine primary care practices in the Tidewater region of Virginia were recruited. The practices, members of a single medical group, and of the Virginia Ambulatory Care Outcomes Research Network (ACORN), share a common type of EMR (GE Centricity Physician Office©) that is managed by a central informatics staff. The practices have used the EMR for 3 to 10 years. Practice size ranged from 1 to 30 clinicians (median = 3), and 48 (87%) clinicians participated in the study. Two sites were solo practices, five had three clinicians, one had eight clinicians, and one (a family medicine residency program) had 30 part-time clinicians and residents.		
Citation(s):	Krist, A. H., Woolf, S. H., Frazier, C. O., et al. An electronic linkage system for health behavior counseling effect on delivery of the 5A's. *American Journal of Preventive Medicine* (2008) 35:S350-S358.		
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CCRM Framework (Table 3-1)
Conceptual Framework Domains and Definitions (Table 3-2)
Master Measurement Table (Table 4-1)

Exhibit 5-19. Measure 19: Connection to resource (Continuity of Care Practices Survey – Practice Level [CCPS-P])

Domain:	Referral Process	**Element/ relationship:**	Clinic/clinician-patient
Instrument:	Continuity of Care Practices Survey – Practice Level [CCPS-P]		
Purpose:	This measure assesses whether clinicians and their staffs participating in the Veterans Affairs Substance Use Disorder (SUD) treatment program were able to arrange for their patient to connect with a community resource.		
Format/data source:	Health professional survey that is completed for each practice by a designated member of that practice.		
Measure type:	Process	**Date:**	2004
Preventive service/ USPSTF:	Alcohol Misuse Counseling		
Clinical practice:	Other		
Denominator:	N/A		
Numerator:	N/A		
Development & testing:	Program-level CCPS data were obtained from directors/coordinators of 129 intensive inpatient/residential and outpatient Department of Veterans Affairs SUD programs. These data were used to examine the internal consistency and discriminant validity of the CCPS-P. CCPS-P demonstrated acceptable psychometric properties. CCPS-P subscales and the overall CCPS-P score predicted corresponding continuity of care services that staff provided to patients within programs, offering support for predictive validity. Lack of significant correlations between CCPS-P subscales and SUD program characteristics (e.g., size, staffing) provided preliminary evidence for discriminant validity.		
Past or validated application:	129 intensive SUD treatment programs (58 inpatient/residential and 71 outpatient); methadone maintenance programs were excluded. Directors of the programs completed the CCPS by mailed questionnaire or telephone interview.		
Citation(s):	Schaefer, J. A., Cronkite, R., Ingudomnukul, E. Assessing continuity of care practices in substance use disorder treatment programs. *Journal of Studies on Alcohol* (2004) 65:513-520.		
Notes	A composite measure using the Connect to Resources Subscale – Add 7A-F (except E) and subtract the number of responses without missing data, e.g., if one item has missing data, subtract 5, the number of complete responses. Please be aware that this measure is using only a selected section of an entire survey instrument. Therefore, this individual measure may need to undergo further reliability and validation testing to ensure that it can be applied in a clinical-community relationship setting.		

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CCRM Framework (Table 3-1)
Conceptual Framework Domains and Definitions (Table 3-2)
Master Measurement Table (Table 4-1)

Exhibit 5-20. Measure 20: Coordination of care (CCPS-P)

Domain:	Feedback and communication	**Element/ relationship:**	Clinic/clinician-community resource
Instrument:	Continuity of Care Practices Survey – Practice Level [CCPS-P]		
Purpose:	This measure assesses whether a clinician and his staff participating in the Veterans Affairs Substance Use Disorder (SUD) treatment program were able to arrange for their patient to connect with a community resource.		
Format/data source:	Health professional survey that is completed for each practice by a designated member of that practice.		
Measure type:	Process	**Date:**	2004
Preventive service/ USPSTF:	Alcohol Misuse Counseling		
Clinical practice:	Other		
Denominator:	N/A		
Numerator:	N/A		
Development & testing:	Program-level CCPS data were obtained from directors/coordinators of 129 intensive inpatient/residential and outpatient Department of Veterans Affairs SUD programs. These data were used to examine the internal consistency and discriminant validity of the CCPS-P. CCPS-P demonstrated acceptable psychometric properties. CCPS-P subscales and the overall CCPS-P score predicted corresponding continuity of care services that staff provided to patients within programs, offering support for predictive validity. Lack of significant correlations between CCPS-P subscales and SUD program characteristics (e.g., size, staffing) provided preliminary evidence for discriminant validity.		
Past or validated application:	129 intensive SUD treatment programs (58 inpatient/residential and 71 outpatient); methadone maintenance programs were excluded. Directors of the programs completed the CCPS by mailed questionnaire or telephone interview.		
Citation(s):	Schaefer, J. A., Cronkite, R., Ingudomnukul, E. Assessing continuity of care practices in substance use disorder treatment programs. *Journal of Studies on Alcohol* (2004) 65:513-520.		
Notes	This is a composite measure using the Coordinate Care Subscale – Add 8A-E and subtract the number of responses without missing data, e.g., if one item has missing data, subtract 4, the number of complete responses. Please be aware that this measure is using only a selected section of an entire survey instrument. Therefore, this individual measure may need to undergo further reliability and validation testing to ensure that it can be applied in a clinical-community relationship setting.		

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CCRM Framework (Table 3-1)
Conceptual Framework Domains and Definitions (Table 3-2)
Master Measurement Table (Table 4-1)

Exhibit 5-21. Measure 21: The effectiveness of communication between practice and community resource (GP-LI)

Domain:	Referral Process	**Element/relationship:**	Clinic/clinician-patient
Instrument:	Capacity for Chronic Disease Management in General Practice Research Study Practice Profile Interview - Linkages with External Organisations of Providers (GP-LI)		
Purpose:	This question assesses the clinician's perception of the effectiveness of communication with the community resource(s).		
Format/data source:	Health professional survey		
Measure type:	Outcome	**Date:**	2005
Preventive service/ USPSTF:	Other – Non-Mental Health*		
Clinical practice:	Primary Care - Family Practice; Primary Care - Internal Medicine		
Denominator:	N/A		
Numerator:	N/A		
Development & testing:	The interview to measure surgery-level (rather than individual clinician-level) clinical linkages was developed, piloted, reviewed, and evaluated with 97 Australian general practices. Two validated survey instruments were posted to patients, and a survey of locally available services was developed and posted to participating Divisions of General Practice (support organizations). Hypotheses regarding internal validity, association with local services, and patient satisfaction were tested using factor analysis, logistic regression, and multilevel regression models.		
Past or validated application:	Setting: General practices in Australia Population: General practitioners and practice managers		
Citation(s):	Amoroso, C., Proudfoot, J., Bubner, T., et al. Validation of an instrument to measure inter-organisational linkages in general practice. *International Journal of Integrated Care* (2007).		
Notes	This question is part of a composite measure for one practice: For each provider or organization the clinician has a linkage with, rate on a scale of 0 – 5 (0 being the lowest and 5 being the highest), the effectiveness of the communication between the two organizations. This tool was originally developed to examine both the clinical and nonclinical links in general practice that exist at a practice level with external providers or organizations. This tool is only designed to look at links that are at the practice level, as defined by a link which the principal GP would tell a new GP about when they joined the practice. The links are recognized in regards to the functions they fulfill, for example, does the practice have a link for referral or advice for asthma. For the purposes of this *Atlas*, the composite scoring was broken and one question was identified as a measure of clinical-community relationships. Please be aware that this measure is using only a selected section of an entire survey instrument. Therefore, this individual measure may need to undergo further reliability and validation testing to ensure that it can be applied in a clinical-community relationship setting.		

* This is a measure that was originally applied in a chronic care setting, but it could be adapted for a primary care setting.Ж

CCRM Framework (Table 3-1)
Conceptual Framework Domains and Definitions (Table 3-2)
Master Measurement Table (Table 4-1)

Exhibit 5-22. Measure 22: The quality of the service provided by community resource to a practice (GP-LI)

Domain:	Knowledge and familiarity with community resources	Element/ relationship:	Clinic/clinician
Instrument:	Capacity for Chronic Disease Management in General Practice Research Study Practice Profile Interview - Linkages with External Organisations of Providers (GP-LI)		
Purpose:	This question assesses a provider's view of the quality of service provided by the community resource(s).		
Format/data source:	Health professional survey		
Measure type:	Outcome	Date:	2005
Preventive service/ USPSTF:	Other – Non-Mental Health*		
Clinical practice:	Primary Care - Family Practice; Primary Care - Internal Medicine		
Denominator:	N/A		
Numerator:	N/A		
Development & testing:	The interview to measure surgery-level (rather than individual clinician-level) clinical linkages was developed, piloted, reviewed, and evaluated with 97 Australian general practices. Two validated survey instruments were posted to patients, and a survey of locally available services was developed and posted to participating Divisions of General Practice (support organizations). Hypotheses regarding internal validity, association with local services, and patient satisfaction were tested using factor analysis, logistic regression, and multilevel regression models.		
Past or validated application:	Setting: General practices in Australia Population: General practitioners and practice managers		
Citation(s):	Amoroso, C., Proudfoot, J., Bubner, T., et al. Validation of an instrument to measure inter-organisational linkages in general practice. *International Journal of Integrated Care* (2007).		

CCRM Framework (Table 3-1)
Conceptual Framework Domains and Definitions (Table 3-2)
Master Measurement Table (Table 4-1)

Exhibit 5-22. Measure 22: The quality of the service provided by community resource to a practice (GP-LI) (continued)

Notes	This question is part of a composite measure for one practice: For each provider or organization the clinician has a linkage with, rate on a scale of 0 – 5 (0 being the lowest and 5 being the highest), the quality of service provided to your practice. This tool was originally developed to examine both the clinical and nonclinical links in general practice that exist at a practice level with external providers or organizations. This tool is only designed to look at links that are at the practice level, as defined by a link which the principal GP would tell a new GP about when they joined the practice. The links are recognized in regards to the functions they fulfill, for example, does the practice have a link for referral or advice for asthma. For the purposes of this *Atlas*, the composite scoring was broken and one question was identified as a measure of clinical-community relationships. Please be aware that this measure is using only a selected section of an entire survey instrument. Therefore, this individual measure may need to undergo further reliability and validation testing to ensure that it can be applied in a clinical-community relationship setting.

* This is a measure that was originally applied in a chronic care setting, but it could be adapted for a primary care setting.

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Appendix A. USPSTF Clinical Preventive Services Included in the Measurement Framework

Table A-1 presents a listing of the services determined to be feasible to deliver in nonclinical settings. These services were guided by the U.S. Preventive Services Task Force (USPSTF) A and B recommendations.

Table A-1. USPSTF clinical preventive services determined to be feasible to deliver in nonclinical settings

Preventive service	Description
Alcohol misuse counseling	The USPSTF recommends screening and behavioral counseling interventions to reduce alcohol misuse by adults, including pregnant women, in primary care settings.
Breastfeeding counseling	The USPSTF recommends interventions during pregnancy and after birth to promote and support breastfeeding.
Obesity screening and counseling – adults	The USPSTF recommends that clinicians screen all adult patients for obesity and offer intensive counseling and behavioral interventions to promote sustained weight loss for obese adults.
Obesity screening and counseling – children	The USPSTF recommends that clinicians screen children aged 6 years and older for obesity and offer them or refer them to comprehensive, intensive behavioral interventions to promote improvement in weight status.
Screening for and management of obesity in adults	The USPSTF recommends that clinicians screen for obesity. Patients with a body mass index (BMI) of 30 kg/m2 or higher should be offered or referred to intensive, multicomponent behavioral interventions.
Sexually transmitted infections (STIs) counseling	The USPSTF recommends high-intensity behavioral counseling to prevent sexually transmitted infections (STIs) for all sexually active adolescents and for adults at increased risk for STIs.
Tobacco use counseling and interventions – non-pregnant adults	The USPSTF recommends that clinicians ask all adults about tobacco use and provide tobacco cessation interventions for those who use tobacco products.
Tobacco use counseling - pregnant women	The USPSTF recommends that clinicians ask all pregnant women about tobacco use and provide augmented, pregnancy-tailored counseling to those who smoke.
Behavioral counseling in primary care to promote physical activity	The USPSTF concludes that the evidence is insufficient to recommend for or against behavioral counseling in primary care settings to promote physical activity.

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Appendix B. National Quality Measures Clearinghouse Data Sources

The data sources are based on the National Quality Measures Clearinghouse (AHRQ, 2011) full listing of data sources.

- Administrative Clinical Data: Data such as enrollment or eligibility information, claims information, and managed care encounters. The claims and encounters may be for hospital and other facility services, professional services, prescription drug services, laboratory services, and so on, gathered from billing codes or other coding systems. This refers to information that is collected, processed, and stored in automated information systems.

- Administrative Management Data: Data that describe attributes of delivery organizations, staff, equipment, nonclinical operations, and financing.

- Clinical Training Documentation: The recording of the details of educational and related activities intended to augment the skills and knowledge of clinical personnel.

- Documentation of Organizational Self-Assessment: An organization's recordkeeping of its identifiable strengths and noticeable gaps in agency performance. The assessment serves to provide agencies with the means to evaluate and understand their own systems and program operations in order to strengthen the services delivered to the community and gain accreditation.

- Electronic Health/Medical Record: In health informatics, an electronic medical record (EMR) is considered to be one of several types of electronic health records (EHRs), but EMR and EHR are also used interchangeably. EHRs are sometimes defined as including other systems that keep track of medical information, such as practice management software that facilitates the day-to-day operations of a medical practice. Such software frequently allows users to capture patient demographics, schedule appointments, maintain lists of insurance payers, perform billing tasks, and generate reports.

- External Audit: A review of a health care organization by a separate organizational entity that examines structures in the health care setting (e.g., facilities, staffing, or the availability of drugs and equipment) or the management of particular clinical or administrative processes.

- Flowsheet: A prospectively maintained tabular or graphic summary in a patient record of changes over time in clinical factors or patient care such as the patient's vital signs, preventive services delivered, or medications prescribed.

- Health Professional Survey: An investigation aimed at gathering information from health professionals to search and disseminate information relating to their professions.

- Inspections/Site Visits: A formal visit to a hospital or heath care facility by representatives from an accrediting organization.

- Laboratory Data: Data collected from a site equipped for experimentation, observation, testing and analysis, or practice in a field of study. In regards to clinical practice, laboratory data may provide information on diagnosis, prognosis, prevention, or treatment of disease based on close examination of the human body.

- Medical Record: That part of a client's health record that is made by physicians and is a written or transcribed history of various illnesses or injuries requiring medical care, inoculations, allergies, treatments, prognosis, and frequently health information about parents, siblings, occupation, and military service. The record may be reviewed by a physician in diagnosing the condition.

- National Public Health Data: Public health data include national health status (gathered through birth and death certificates, hospital discharge diagnoses, other epidemiologic sources), communicable disease (food/water/air/waste/vector borne), environmental health risks, presence of and use of health care facilities and providers, preventive services, and other information identified by the nation as helpful for planning.

- Organizational Policies and Procedures: Refers to the principles and methods, whether formalized, authorized, or documented, that enable people affiliated with an organization to perform in a predictable, repeatable, and consistent way.

- Patient/Individual Survey: An instrument that assesses patients' perspectives on any of the following: their health and the care they receive, including the level of patients' satisfaction, or patients' understanding of their health status.

- Pharmacy Data: A database that provides information on prescription and/or dispensing of drug and non-drug products that may be obtained from a pharmacy (retail or health care institution-based).

- Provider Characteristics: Specific descriptive information about the clinician provider or the facility caring for the patient.

- Region, County, or City Public Health Data: Public health data include community health status on a region/county/city level (gathered through birth and death certificates, hospital discharge diagnoses, local surveys, other epidemiologic sources), communicable disease (food/water/air/waste/vector borne), environmental health risks, presence of and use of health care facilities and providers, preventive services, and other information identified by the local community as helpful for planning.

- Registry Data: An organized system that uses observational study methods to collect uniform data (clinical and other) to evaluate specified outcomes for a population defined by a particular disease, condition, or exposure, and that serves one or more predetermined scientific, clinical, or policy purposes.

- Special or Unique Data: A data source that is unique to an organization and inaccessible to outside entities or persons.

- State/Province Public Health Data: Public health data include community health status on a State/province level (gathered through birth and death certificates, hospital discharge diagnoses, statewide and local surveys, other epidemiologic sources), communicable disease (food/water/air/ waste/vector borne), environmental health risks, presence of and use of health care facilities and providers, preventive services, and other information identified by the community as helpful for planning.

- Other: Another data source that does not fit any of the criteria listed above.

- Not Specified: The reference/Web site did not indicate how measure data were to be collected.

Appendix C. Environmental Scan Process

The environmental scan focused on identifying previous work that may be relevant to measuring the structures and processes surrounding effective clinical-community relationships for prevention. A resource was deemed relevant if it highlighted some form of relationship between a clinical and community resource and evaluated the relationship in some manner. Beyond surveying published peer-reviewed articles, unpublished literature such as dissertations, white papers, and other forms of publicly available information were included in the search. The environmental scan was performed in two phases—a literature review and a Web search. The scan did not evaluate identified resources for the quality of methods used or research rigor.

For the literature review, iterative database searches were conducted. Various combinations of terms were searched and citation titles and abstracts were scanned to determine if the content related to measures of clinical-community relationships. As part of the search strategy, the following search parameters and terms were employed to facilitate the scanning of databases:

Search Parameters. The following parameters for database searches of published literature were employed:

- English language;
- 2000–present;
- United States and international; and
- Exclusion of editorials, commentaries, and book reviews.

Search Terms. A list of keywords was generated and then grouped into four categories:

- Terms relating to community resources;
- Terms dealing with clinical practices;
- Terms describing relationships; and
- Terms related to measures.

Table C-1 contains a complete list of search terms used for both the literature review and the Web search.

Table C-1. Search terms for literature review and Web search

Community organizations/ services/resources	Primary clinical practices	Relationships	Measurement
Community Health	Medical Home	Relationships	Measure
Clinical Preventive Services	Clinic	Partnerships	Performance
Health Department	Internist	Linkages	Evaluate
Practice-Based Public Health	Pediatrics	Collaborations	Performance Results
Health Promotion	OB/GYN	Coalitions	Track
Community Wellness	Primary Care	Networks	Survey/Surveillance
Directive Counseling	Family Practice	Coordination	Assessment
Community-Based Participatory Research (CBPR)	Primary Physician	Systems	Analysis
Patient Education	Primary Medicine	Referrals	Effectiveness
Faith-Based Organization		Exchanges	Metric
Community Involvement		Communication	
Community Center		Cooperate	
Grassroots Organization		Sharing	
Community Program		Connection	
Community Resources		Care Coordination	
Workplace Wellness			

To operationalize the search, Boolean operators (i.e., AND, OR) between each of the keywords and their categories were used. Within an article, the goal was to find at least one of the terms within the column; thus, using “OR” between all of the terms within a column. There was also an interest in the combination of terms across columns, therefore the “AND” term was used for terms across columns. For example, a search incorporating both concepts of measurement and relationships would proceed as follows: (“effectiveness” OR “metric” OR “measurement” OR “evaluation”) AND (“referrals” OR “sharing” OR “system” OR “linkage”). Further, variants of the search terms were included; for example, “medical home” and “medical homes.” Along with the four categories mentioned, exact phrases were searched, including “clinical community relationships,” “clinical community linkages,” and “clinical community partnerships.”

Experts were also identified in the field of clinical-community relationships and a search of publications since 2007 was conducted; these experts are listed in Table C-2.

Table C-2. Experts identified for author search

Expert	Expert
Melinda K. Abrams, MS	Russell E. Glasgow, PhD
Richard C. Antonelli, MD, MS, FAAP	Lawrence W. Green, DrPH
Cheryl B. Aspy, MEd, PhD	Charles J. Homer, MD, MPH
Stephanie B. Bailey, MD, MSHSA	David Labby, MD, PhD
Leslie M. Beitsch, MD, JD	Therese Miller, DrPH
Peter Beilenson, MD	Amy Schultz, MD, MPH
Allen D. Cheadle, PhD	Ruta K. Valaitis, RN, PhD
Rebecca S. Etz, PhD	Claire Weschler, MSEd, CHES
Janice L. Genevro, PhD	

Using the search terms from Table C-1 and the parameters mentioned above, the following electronic databases were scanned:

- **Applied Social Sciences Index and Abstracts (ASSIA).** Covers health, social services, psychology, sociology, economics, politics, race relations, and education literature.

- **FirstSearch.** A Web-based online information service that provides access to bibliographic and full-text databases in all subject disciplines.

- **Health and Psychosocial Instruments (HAPI).** Provides information on measurement instruments (i.e., questionnaires, rating scales, tests, index measures, coding schemes, checklists) in the fields of public health and medicine, psychosocial sciences, communication, organizational behavior, and others. HAPI records do not contain the actual instruments, but often direct the researcher to sources of measures needed for research, assessment, and evaluation.

- **PsycINFO.** Covers international literature in the psychological, psychiatric, social, behavioral, and health sciences.

- **PUBMED.** Covers all aspects of health and medical literature.

For the Web search, using similar search queries to those for the database, the first 20 links were reviewed for possible clinical-community relationships. Further, the Web sites highlighted in Table C-3 were reviewed.

Table C-3. Targeted organization Web sites

Measurement Organization
National Quality Measures Clearinghouse (NQMC)
National Quality Forum (NQF)
Continuous Enhancement of Quality Measurement (CEQM)
National Committee for Quality Assurance (NCQA)
Physician Consortium for Performance Improvement (PCPI)
Government Agencies
Agency for Healthcare Research and Quality (AHRQ)
Centers for Disease Control and Prevention (CDC)
Community Preventive Services Task Force
Health Resources and Services Administration (HRSA)
Public and Private Organizations
Robert Wood Johnson Foundation (RWJF)
W.K. Kellogg Foundation (WKKF)
Kaiser Family Foundation (KFF)
Practitioner and Public Health-Related Organizations
American Medical Association (AMA)
American Academy of Family Physicians (AAFP)
American Public Health Association (APHA)
American College of Preventive Medicine (ACPM)
American Academy of Pediatrics (PPC)
Other Prevention Partnerships
Association of Prevention Teaching and Research (APTR)
Association of State and Territorial Health Officials (ASTHO)
National Association of County and City Health Officials (NACCHO)

The following specific inclusion/exclusion criteria were used to select relevant resources for further review:

- Must contain a linkage or relationship between a clinical setting (internal medicine, pediatrics, family practice, OB/GYN) and a community health organization;
- Must contain a description of a measurement or an evaluation of the linkage/relationship between the clinical setting and the community health organization; and
- Should not only report on the evaluation of the health outcomes of patients/participants (e.g., changes in body mass index [BMI], weight loss, quit cessation rates, etc.) – those that did were not included in the list of relevant articles.

Once resources were identified, a review team determined whether the selected articles or Web Sites contained measures of the structures and processes surrounding effective clinical-community relationships for prevention. In order to determine this, the articles were analyzed for the following information:

- **Clinical Setting.** What clinical setting participated in the relationship? The clinical setting must focus on primary care.
- **Prevention.** What prevention strategy is the relationship addressing? Specifically, which U.S. Preventive Services Task Force recommendation(s)?
- **Community Setting.** What nonclinical community resource/entity participated in the relationship?
- **Nature of Relationship.** Is there a formal relationship between/among the clinical setting and community? Are resources shared? What processes fostered the relationship?
- **Denominator.** Specifies which members of the eligible population are to be counted in the denominator.
- **Numerator.** A count of the members of the denominator who achieved specified outcomes.
- **Data Source(s).** How are the data collected? This may include claims data, community assessments, or surveys.

A total of 534 unduplicated abstracts were reviewed and, ultimately, 9 articles describing 20 measures were included from the literature search. An additional 4 measures were found in the Internet search for a combined total of 24 measures. Initially, only articles describing a linkage or relationship between a primary care clinical setting and a nonclinical community organization were included. Articles that focused on mental health settings were ultimately included, however, but only when it was determined that measures from these articles could be adapted for primary care settings.

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Appendix D. Clinical-Community Relationships Measures Instruments

Safety Check Parental/Guardian Post-Visit Survey

***CCRM Atlas* Measure(s): 1, 2, 3**

Contact Information:

Contact information unavailable.

Copyright Details:

These surveys were developed by Dr. Shari Barkin in conjunction with colleagues from the Pediatric Research in Office Settings (PROS) network. The study was funded by the National Institute of Child Health and Human Development (R0l HD 42260), the Agency for Healthcare Research and Quality, the Health Resources and Services Administration Maternal and Child Health Bureau, the Robert Wood Johnson Generalist Faculty Scholars Program, and the American Academy of Pediatrics’ (AAP) Friends of Children Fund. They are reprinted with permission from the AAP.

PARENT/GUARDIAN POST-VISIT SURVEY

Please answer before leaving your doctor's office**.**

1. **What topics did your child's doctor discuss with you today? (please check all that apply)**
   - ☐ TV/computer games/video watching
   - ☐ Discipline
   - ☐ Bike helmets
   - ☐ Drowning prevention
   - ☐ Reading aloud
   - ☐ Family fights
   - ☐ Care of teeth
   - ☐ Car seats/seat belts
   - ☐ Smoking around your child
   - ☐ Guns around children
   - ☐ Storing medicines or home cleaning products
   - ☐ Child nutrition
   - ☐ Regular exercise
   - ☐ None of the above

2. **Did you receive a …** (check one box for each)

a. Recommendation Guide?	☐	Yes	☐	No
b. Minute Timer?	☐	Yes	☐	No
c. Cable Lock?	☐	Yes	☐	No
d. Local Agency Referral?	☐	Yes	☐	No

Please answer these next questions on a scale from 1-5, with "1" indicating "Not at all interested" and "5" indicating "Very interested. **(check one box for each question)**

3. **How interested are you in ...**

	Not at all interested	Somewhat interested	Neutral	Interested	Very interested	Doesn't apply
a. using the minute timer for time-out/cool-down periods?	☐	☐	☐	☐	☐	☐
b. using the minute timer to limit media use?	☐	☐	☐	☐	☐	☐
c. installing a cable lock(s) on gun(s)?	☐	☐	☐	☐	☐	☐
d. following up on the local agency referral?	☐	☐	☐	☐	☐	☐

4. How confident are you that you will be able to use a ...

	Not at all interested	Somewhat interested	Neutral	Interested	Very interested	Doesn't apply
a. using the minute timer for time-out/cool-down periods?	☐	☐	☐	☐	☐	☐
b. using the minute timer to limit media use?	☐	☐	☐	☐	☐	☐
c. a cable lock(s)	☐	☐	☐	☐	☐	☐
d. local agency referral?	☐	☐	☐	☐	☐	☐

Thank you! We'll contact you in 1 month and 6 months.

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Safety Check Practitioner Post-Visit Survey

***CCRM Atlas* Measure(s): 4, 5, 6**

Contact Information:

Contact information unavailable.

Copyright Details:

These surveys were developed by Dr. Shari Barkin in conjunction with colleagues from the Pediatric Research in Office Settings (PROS) network. The study was funded by the National Institute of Child Health and Human Development (R0I HD 42260), the Agency for Healthcare Research and Quality, the Health Resources and Services Administration Maternal and Child Health Bureau, the Robert Wood Johnson Generalist Faculty Scholars Program, and the American Academy of Pediatrics' (AAP) Friends of Children Fund. They are reprinted with permission from the AAP.

PRACTITIONER POST-VISIT SURVEY

FOR THE PRACTITIONER:
Please answer these questions now that you are finished with this child's exam.

1. **When was this patient's first contact with your practice?** __/______
   Month Year

2. **This patient is:** (select best response)
   - ☐ My primary care patient
   - ☐ In our practice
   - ☐ Self-referred (from another practice)
   - ☐ Referred by another provider
   - ☐ ____________________________ Other:

3. **What topics did you discuss today with this patient's family?**
   (check **all that apply**)
   - ☐ TV/computer games/video watching
   - ☐ Discipline
   - ☐ Bike helmets
   - ☐ Drowning prevention
   - ☐ Reading aloud
   - ☐ Family fights
   - ☐ Care of teeth
   - ☐ Car seats/seat belts
   - ☐ Smoking around your child
   - ☐ Guns around children
   - ☐ Storing medicines or home cleaning products
   - ☐ Child nutrition
   - ☐ Regular exercise
   - ☐ None of the above

4. **Did you provide a . . .** (check one box for each)
   - **a.** Recommendation Guide? ☐ Yes ☐ No
   - **b.** Minute Timer? ☐ Yes ☐ No
   - **c.** Cable Lock? ☐ Yes ☐ No
     - **If yes**, how many? __________
   - **d.** Referral? ☐ Yes ☐ No ☐ Unable (no appropriate resources in community)
     - **If yes**, what was it for? (check all that apply)
       - ☐ Behavioral Problems
       - ☐ Anger Management
       - ☐ Other ______________
     - **If yes**, to… (check all that apply)
       - ☐ Mental Health Professional (e.g,, psychologist)
       - ☐ Parenting Classes
       - ☐ Local Agency Resource (e.g,, Boys & Girls Club)
       - ☐ Other ______________________

Please answer these next questions on a scale from 1-5, with “1” indicating “Not at all interested” and “5” indicating “Very interested.” (check one box for each question)

5. How interested do you think the family was in following your recommendations about …

	Not at all interested	Somewhat interested	Neutral	Interested	Very interested	Doesn’t apply
a. using the minute timer for time-outs/cool-down periods?	☐	☐	☐	☐	☐	☐
b. using the minute timer to limit media use?	☐	☐	☐	☐	☐	☐
c. using a cable lock(s)?	☐	☐	☐	☐	☐	☐
d. following up on the local agency referral?	☐	☐	☐	☐	☐	☐

6. How confident were you in your ability to instruct this patient-family in the proper use of …

	Not at all confident	Somewhat confident	Neutral	Confident	Very confident	Doesn’t apply
a. minute timer for time-outs/ cool-down periods?	☐	☐	☐	☐	☐	☐
b. minute timer to limit media use?	☐	☐	☐	☐	☐	☐
c. a cable lock(s)?	☐	☐	☐	☐	☐	☐
d. local agency referral?	☐	☐	☐	☐	☐	☐

PLEASE GIVE THIS SURVEY TO YOUR OFFICE COORDINATOR THANK YOU!

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Wrap-Around Observation Manual – Second Version

***CCRM Atlas* Measure(s): 7, 8**

Contact Information:

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Wraparound Observation Manual- Second Version

MICHAEL H. EPSTEIN

PHILIP D. NORDNESS

MELODY HERTZOG

JANUARY 2002

(DRAFT 7)

Observation Manual

1. **Information about resources/interventions in the area is offered to the team.**

*The team mentions at least one specific resource/intervention (e.g., A.A, vocational rehab, Teammates) to the parent or asks if the parent is involved or needs community resources/intervention. The team provides specific information about accessing these resources/interventions if the parent expresses a wish to utilize the resource/intervention. *Parent need not be present for a Yes response to occur.*

SCORING

1. **Yes** if the team mentions or asks if the parent is involved in resources/interventions. Score **Yes** if the team asks about or mentions resources/interventions and the parent is already involved or does not show an interest in such services, and thus the team does not provide contact information.

2. **No** if the team mentions support resources/interventions but does not provide a contact person/number or the parent expresses an interest in accessing the resource/intervention, but it is not followed up by the team.

2. **Plan of care includes at least one public and/or private community service/resource.**

The team specifically identifies at least one public (e.g., HHS, Lincoln Public Schools, SSI) and/or private (e.g., private therapists/counselors, drug rehab centers) community service/resource in the plan of care. It is clear that these services are easily accessible from the family's home community (i.e., no services are far from home community).

Scoring

1. **Yes** only if one public and/or private service is included in the plan. These agencies must be accessible from the client's community.

2. **No** if at least one public and/or private services in the client's community are not included in the plan.

3. Plan of care includes at least one informal resource.

The team specifically identifies at least one informal resource (e.g., YMCA, Big Brother/Big Sister, recreation program, family member providing respite). It is clear that the resource is not provided by a public agency. If service is purchased by flexible funds it is a formal resource.

Scoring

1. **Yes** only if one informal resource is included in the plan.
2. **No** if at least one informal resource in the child/family community is not included in the plan.

4. When residential placement is discussed, team chooses community placements for child (children) rather than out-of-community placements, whenever possible.

The team discusses, recommends, and plans for community placement. Out-of-community placements are not recommended or planned for unless no home community alternative exists.

Scoring

1. **Yes** if the placement the team recommends and plans for the child/family is in the community.
2. **No** if the team plans for a placement that is out of the community.
3. **NA** if residential placement is not discussed.

5. **Individuals (non-professionals) important to the family are present at the meeting.**

Individuals important to the family and who are from the family's community or natural support system are present at the meeting. This may include extended family members, community leaders, ministers, and friends. However, professional service providers (e.g., therapists, homemakers) are not *considered here.*

Scoring

1. **Yes** if at least one individual like those described above attends the meeting.
2. **No** if no individual like those described above attends the meeting.

6. **If an initial plan of care meeting, the parent is asked what treatments or interventions he/she felt worked/didn't work prior to F3.**

The team explicitly asks the parent what services, treatments or interventions (e.g., drug treatment, psychotherapy, medication, vocational training, token economy) that have been attempted in the past worked or did not work. Treatments or interventions include only formal services received by the family.

Scoring

1. **Yes** if the team asks the parent about previous services, intervention(s) or treatments.
2. **No** if question is not asked.
3. **NA** if family has never received services, or, if this is not an initial plan of care meeting, past events may not be discussed.

7. **Care Coordinator advocates for services and resources for the family (e.g., identifies and argues for necessary services).**

At least one Care Coordinator assertively identifies (i.e., continues to state the importance of) a necessary service for the family and is persistent in securing (or persists in attempting to secure) that service. If other professionals disagree, at least one Care Coordinator continues to convey the importance of that service or resource to the team.

<u>Scoring</u>

1. **Yes** if at least one Care Coordinator worker assertively identifies (to the team) a needed service or intervention for the family member AND continues to pursue the importance of that service (when necessary) even if others (e.g., team members) disagree.

2. **No** if needed services or interventions are not identified by a Care Coordinator worker OR services or interventions are identified but their importance is not pointed out when necessary.

8. **All services needed by family are included in plan (i.e., no needed services were not offered).**

All services the family and team identifies as necessary for the family are written into the plan of care. The team does not exclude a needed service from the plan.

<u>Scoring</u>

1. **Yes** if all identified needed services are included in the plan of care.

2. **No** if the team excludes from the plan of care <u>any</u> service needed by the family.

9. Barriers to services or resources/interventions are identified and solutions discussed.

If barriers were identified team members discuss possible solutions. Examples of barriers include transportation, funding, location, eligibility, etc. Solutions may not be possible but at least one solution must be discussed.

Scoring

1. **Yes** if at least one barrier identified and solution discussed.

2. **No** if at least one barrier identified and no solution discussed.

3. **NA** does not apply if no barriers were identified.

10. The steps needed to implement the plan of care are clearly specified by the team.

The team clearly specifies the steps needed to implement the plan. Specific services, resources, interventions, or other actions are discussed in specific behavioral/operational terms. Examples would include the steps needed to attend outpatient therapy once a week, or attend drug therapy once a week, or how to obtain public aid or food stamps.

Scoring

1. **Yes** if the team clearly specifies (i.e., in behavioral/operational terms) how the plan of care will be implemented.

2. **No** if the steps for achieving service plan goals are not specified, or if they are specified only in general terms, without mention of specific interventions, services, resources and/or actions to be taken.

11. Strengths of family members are identified and discussed at the meeting.

Care Coordinators identify and discuss the behavioral, emotional, familial, and/or social strengths of individual family members or of the family unit. A strength can include a skill, action, and/or knowledge competency.

Scoring

1. **Yes** if a strength of at least one family member is identified and addressed at the meeting.

2. **No** if no strength of at least one family member is identified and addressed at the meeting. Merely complimenting a youth in a general manner is scored a No.

12. Plan of care that includes life domain(s), goals, objectives, and resources/interventions is discussed (or written).

Life domain(s), goals, objectives, and resources/interventions necessary for child/family's plan of care are discussed.

Scoring

1. **Yes** if the goals(s), objectives, and resources/interventions for at least one life domain are completed/discussed and agreed upon by team members.

2. **No** if a goal(s), objective, and resource/intervention for at least one life domain is excluded or at least one life domain is not completed.

3. **NA** if this is a discharge meeting.

13. Plan of care goals, objectives, or interventions are based on family/child strengths.

Team develops (discusses or writes) plan of care based on strengths of the child or family member.

Scoring

1. **Yes** if at least one goal or objective in plan is developed (or written) based on at least one strength of the child or a family member.
2. **No** if plan of care is developed (or written) without being based on child or family strength.
3. **NA** if this is a discharge meeting.

14. Safety plan/crisis plan developed/reviewed.

Safety plan/crisis plan to protect the safety of the child/family or to implement in the event of a crisis is discussed, written or reviewed. Crisis may include but is not limited to substance abuse, running away, hospitalization, domestic violence, etc.

Scoring

1. **Yes** if the team clearly specifies (i.e., in behavioral/operational terms) the goals, objectives and resources/interventions in discussing, writing or reviewing of a safety plan/crisis plan.
2. **No** if the steps for implementing a safety plan/crisis plan are not specified, or if they are specified only in general terms without mention of specific interventions, resources, or services.
3. **NA** does not apply if child/family safety is not an issue or if child/family are not expected to experience a crisis.

15. Convenient arrangements for family's presence at the meeting are made (e.g., location, time, transportation, day care arrangements).

F3 staff arranged the meeting at a time convenient to at least one family member and transportation to the meeting and day care were offered, if necessary.

Scoring

1. **Yes** if it is evident that F3 workers scheduled the meeting at a time that at least one family member was available to attend AND transportation and day care was offered if the family needed it.

NOTE: If this is not alluded to, the observer may have to ask the family members if this occurred (AFTER the meeting).

2. **No** if it is not evident that efforts were not made by F3 staff to schedule the meeting at a time convenient to family OR score **No** if they provided a time that was convenient but neglected to offer transportation or day care if needed.
3. **NA** if observer cannot ascertain whether or not family was consulted about the meeting or observer cannot speak with family member or if child/family member is not present.

16. The parent/child is seated or invited to sit where he/she can be included in the discussion.

The parent/child is seated where he/she is not isolated from the rest of the group and is seated in a size-appropriate chair. If the parent/child does not initially sit with the group, the team invites him/her to do so.

Scoring

1. **Yes** if the parent/child is seated where he/she is not isolated from the rest of the group and is seated in a size-appropriate chair. Also, **Yes** if the parent is seated away from the group but has been invited to sit with the group.
2. **No** if the parent/child is not seated with the group and was not invited to do so. Also, **No** if parent/child is seated in a chair that is too small.
3. **NA** if child/family member is not present.

17. Family members are treated in a courteous fashion at all times.

Examples include, but are not limited to: The team establishes eye contact with family members, family is listened to, the team speaks to family members in a calm, non-confrontational tone of voice.

Scoring

1. **Yes** if the team interacts with the family courteously at all times.

2. **No** if the team is not courteous to the family at all times (give specific instance by writing on form.)

3. **NA** if family members are not present.

18. The family's perspective is presented to professionals from other agencies.
(*If NA, include 25, 28, 29)

Care Coordinator(s) ensures that the family's view of their problems/situation is presented to all other professionals at the meeting. This can be either a) Care Coordinator speaks on behalf of the family or b) family members are given time to speak for themselves. Family's perspective includes such areas as identifying needs, strengths, goals, services required, etc.

Scoring

1. **Yes** if the family's point of view is expressed by either Care Coordinator or the family themselves.

2. **No** if the family's point of view is not discussed at any time in the meeting.

3. **NA** if other professionals are not present.

19. The family is asked what goals they would like to work on.

The team explicitly asks the family about what goals they would like help with. This could include (but is not limited to) asking the family what they would like to work on, improve, or change.

Scoring

1. **Yes** if the team asks this type of question.

2. **No** if question is not asked.

3. **NA** if the family is not present.

20. The parent is asked about the types of services or resources/interventions he/she would prefer for his/her family.

The team specifically asks the parent about the types of services or resources/interventions he/she would or would not want to be used with their family. Examples include medication, psychotherapy, homemaker services, drug counseling, housing, vocational training.

Scoring

1. **Yes** if the team asks the parent about the services or resources/interventions he/she would prefer.

2. **No** if question is not asked.

3. **NA** if the child or family is not present.

21. Family members are involved in designing the plan of care.

The family's ideas about the plan of care are elicited by the team. The family is allowed to contribute ideas in the formulation of the plan of care. The team specifically asks the parent/child to participate in the design of the plan of care.

Scoring

1. **Yes** if the team allows and asks the parent to contribute ideas to the design of the plan of care.

2. **No** if the team does not allow **nor** asks family members contributions.

3. **NA** if family is not present.

22. In the plan of care, the family and team members are assigned (or asked) tasks and responsibilities that promote the family's independence (e.g., accessing resources on own, budgeting, maintaining housing).

Team members write goals or objectives in the plan of care that require family members to complete tasks and accept responsibilities that will help build their independence from formal service providers. Examples include taking GED classes, enrolling in vocational training, learning to budget, etc.

Scoring

1. **Yes** if at least one family member is assigned tasks and responsibilities that will enable him/her to increase their level of independence from formal service providers.

2. **No** if the team does not assign tasks/responsibilities to any family member in the plan.

3. **NA** if family is not present.

23. The team plans to keep the family intact or to reunite the family.

The team writes goals or objectives in the plan of care that outline the steps necessary for either a) keeping the family intact OR b) reuniting family members in placement. Look at plan of care (permanency plan) to see that it states that the family will be reunited or remain intact.

SCORING

1. **Yes** if goals or objectives are written in the plan of care to fulfill either of the above criteria. (This question refers to the child remaining or reuniting with one or both of the parents. A child moving in with a brother or sister would not qualify as a Yes.)

2. **No** if the team does not include goals or objectives in the plan of care that is not directed towards family preservation (keeping family intact, reunification).

3. **NA** if reunification is not an option for the family (e.g., parents rights have been severed, permanent foster care is the child's goal) or if child is age of majority.

24. Family members voice agreement/disagreement with plan of care.

As the plan of care is being developed a family member states whether he/she agree/disagree with the plan's goals, objectives, and/or resources/interventions. Family member(s) statements may be unsolicited or solicited by Care Coordinator or team member.

SCORING

1. **Yes** if the family member voices opinion with plan of care's goals, objectives, and/or interventions/resources.

2. **No** if the family member does not voice an opinion or Care Coordinator does not solicit opinion.

3. **NA** if the family member is not present.

25. Staff from other agencies who care about or provide resources/interventions to the family are at the meeting.

At least one professional (other than F3 care coordinator) that provides services is present at the meeting.

Scoring

1. **Yes** if at least one professional from another agency is present at the meeting.
2. **No** if no outside professional(s) attend the meeting.

26. Staff from other facilities or agencies (if present) have an opportunity to provide input.

If professionals from other facilities or agencies are present, the team specifically asks them to provide input.

Scoring

1. **Yes** if professionals volunteer input for the plan, or if the team specifically asks other non-F3 professionals to provide input, even if other professionals do not provide any.
2. **No** if the team does not ask for input from other non-F3 professionals present at the meeting.
3. **NA** if professionals from other agencies are not present at meeting.

27. Informal supports (if present) have an opportunity to provide input.

If informal supports are present, the team specifically asks them to provide input.

<u>Scoring</u>

1. **Yes** if informal supports volunteer input for the plan, or if the team specifically asks at least one informal support to provide input.

2. **No** if the informal supports do not volunteer input for the plan or if the team does not solicit input from at least one informal support.

3. **NA** if informal supports are not present.

28. Problems that can develop in an interagency team (e.g., turf problems, challenges to authority) are not evident or are resolved.

There are no obvious conflicts among team members OR if conflicts between professionals arise, team members identify them and make every effort to achieve their resolution.

<u>Scoring</u>

1. **Yes** if there are no conflicts among professionals OR if problems arise, Care Coordinator acknowledges them and makes reasonable efforts to resolve them.

2. **No** if conflicts arise and attempts are <u>not</u> made to resolve them OR if conflicts are identified but there is little effort towards finding agreement.

3. **NA** if professionals from other agencies are not present.

29. Staff from other agencies describes support resources/interventions available in the community.

If professionals from other agencies are present, they volunteer or are asked by the Care Coordinator to identify support resources/interventions available in the community.

Scoring

1. **Yes** if a professional provides information (either voluntarily or being solicited) on support resources/interventions available in the community.

2. **No** if a professional does not provide information on support resources/interventions in community or if such information is not solicited by Care Coordinator or other team member.

3. **NA** if professionals from other agencies are not present.

30. Statement(s) made by a staff member or an informal support indicates that contact/communication with another team member occurred between meetings.

Verbal (e.g., telephone, in person) or written communication between two or more team members (i.e., professional/informal supports) occurred between the last and present meeting.

Scoring

1. **Yes** if verbal or written communication occurred between two or more team members.

2. **No** if verbal or written communication did not occur between two or more team members or it is not evident.

3. **NA** if professionals/informal supports are not present or initial meeting.

31. Availability of alternative funding sources is discussed before flexible funds are committed.

Team member(s) discuss alternative sources of funding (e.g., Medicaid, community grants, United Way, juvenile justice) before using flexible funds. If it is not clear whether flex funds were being discussed or used ask the care coordinator.

<u>Scoring</u>

1. **Yes** if at least one alternative funding source is discussed.
2. **No** if no alternative funding source is discussed.
3. **NA** if funding of services or resources/interventions is not discussed.

32. Termination of F3 Services is discussed because of the multiplicity or severity of the child's/family's behaviors/problems.

Team discusses termination of F3 services based solely on the severity or number of difficult behaviors/problems experienced by the family or any of its members.

<u>Scoring</u>

1. **Yes** if termination is discussed.
2. **No** if termination is not discussed.
3. **NA** mark NA if termination is discussed because of funding issues, or if a family is, at that time, not presenting significant behavioral issues.

33. Termination of other services (non-F3 services) is discussed because of the multiplicity or severity of the child's/family's behavioral problems.

Team discusses termination of other services (non-F3) based solely on the severity or number of difficult behaviors/problems experienced by the child/family.

Scoring

1. **Yes** if termination of other services is discussed.
2. **No** if termination of other services is not discussed.
3. **NA** mark NA if a family is, at that time, not presenting significant behavioral issues.

34. For severe behavior challenges (e.g., gangs, drugs) discussion focuses on safety plans/crisis plans (e.g., services and staff to be provided) rather than termination.

When discussing severe behavior problems (e.g., gang activity or drug abuse), Care Coordinator talks about possible solutions, additional services or increasing intensity of services. Discharge is not identified as an option.

Scoring

1. **Yes** if team discusses, writes or refers to the safety/crisis plan.
2. **No** if team does not discuss, write or refer to the safety/crisis plan, or if termination is discussed.
3. **NA** does not apply if severe behavior challenges are not discussed.

35. The plan of care goals are discussed in objective, measurable terms.

The goals that are discussed define changes in behavior, living situation, placement, etc. Goals are described in objective, behavioral terms. Target behaviors are clearly identified and defined in behavioral terms.

Scoring

1. **Yes** if plan of care goals are discussed in a way that meets the criteria in the above definition.

2. **No** if plan of care goals are not discussed, **or** if they are discussed only in general, non-specific terms.

3. **NA**, if a discharge meeting.

36. The criteria for ending F3 involvement are discussed.

The team discusses the criteria in terms of the discharge from services (i.e., from F3). Level of achievement is clearly defined in behavioral terms. The team discusses the time period during which services will be provided.

Scoring

1. **Yes** if the team discusses the criteria for discharge of services in clear, specific, and behavioral terms. The discussion should be focused on specific criteria that need to be achieved within a specified time period.

2. **No** if termination of services is not discussed, or if it is discussed only in general, non-behavioral terms.

3. **NA** if the family has received services from F3 for 6 months or less.

37. Objective or verifiable information on child and parent functioning is used as outcome data.

Specific behaviors or actions of the child, parent, and/or other family members are identified and used by team members as a measure to assess whether or not the goals/objectives in the plan of care have been achieved. For example, a parent providing adequate supervision of her children, a parent secures public aid for her/his family, a child's school attendance increases, etc.

Scoring

1. **Yes** if team members discuss specific child/parent behaviors and use these behaviors as criteria for rating the client's progress toward a goal/objective in the plan of care.

2. **No** if the team does not use child/parent behaviors as criteria for rating client's progress towards a goal/objective in the plan of care.

38. Key participants are invited to the meeting (i.e., family members, CPS worker, teacher, therapist, others identified by the family).

Care Coordinator has invited the necessary participants to the family meeting. This includes: family members, professionals and paraprofessionals involved with the family, and members of the family's natural or informal support system or community.

Scoring

1. **Yes** if it is mentioned or implied that the Care Coordinator has invited at least 2 key people other than F3 staff and immediate family members to the meeting.

NOTE: The observer may need to ask Care Coordinator who was invited AFTER the meeting.

2. **No** if it is evident that at least two key participants were not invited.

3. **NA** if a team has not been assembled yet.

39. **Current information about the family (e.g., social history, behavioral and emotional status) is gathered prior to the meeting and shared at the meeting (or beforehand).**

There is enough basic demographic and current functioning information about the family, such as name, date of birth, current identifying information and current functioning data, so that the meeting can proceed in a timely manner, without undue time being spent gathering this information. It is clear that this information was gathered prior to the meeting <u>*and*</u> *shared with meeting participants (or beforehand).*

<u>Scoring</u>

1. **Yes** only if the two criteria (information gathered and shared) in the definition are met.

2. **No** if one of these two criteria is not met.

40. **All meeting participants introduce themselves (if applicable) or are introduced.**

Everyone present at the start of the meeting states his or her name and agency/occupation (e.g., psychiatrist, probation officer, HHS worker).

<u>Scoring</u>

1. **Yes** only if **<u>all</u>** meeting participants state their name and agency or occupation (role) at the start of the meeting.

2. **No** if only some of the participants introduce themselves or if they only state their name but not their occupation (role).

3. **NA** does not apply if all team members have worked with family for a reasonable period of time (i.e., 4 months based on enrollment date).

41. The family is informed that they may be observed during the meeting.

The family is told that he/she may be observed during the meeting by the evaluation staff. The team explains to the parent that the observers are there to assess the Care Coordinator's performance and that all note taking reflects staff actions, not client information.

NOTE: If not mentioned at meeting, observer will ask parent if they were informed of the observer's presence prior to the meeting.

Scoring

1. **Yes** if the family is told that he/she is being observed and why.

2. **No** if an observer is present and the family is not informed **and** told why.

3. **NA** if family member is not present OR if the observer has missed the beginning of the meeting, or is unable to ascertain whether or not these criteria have been met.

42. Plan of care is agreed on by all present at the meeting.

All meeting participants agree to a plan of care by the end of the meeting.

Scoring

1. **Yes** if the service plan is agreed upon either implicitly or explicitly by all present.
2. **No** if the service plan is not agreed upon either implicitly or explicitly by all present.

43. Care Coordinator makes the agenda of meeting clear to participants.

At the beginning of meeting Care Coordinator states the agenda and purpose of meeting to those in attendance.

Scoring

1. **Yes** if Care Coordinator verbalizes or hands out printed agenda.

2. **No** if written or verbal agenda is not provided by Care Coordinator.

3. **NA** if the observer has missed the beginning of the meeting.

44. Care Coordinator reviews goals, objectives, interventions, and/or progress of plan of care.

Present plan of care is reviewed by Care Coordinator for the participants early in the meeting.

Scoring

1. **Yes** if Care Coordinator reviews (verbally or in writing) present plan of care for team early in the meeting.

2. **No** if Care Coordinator does not review present plan or reviews plan later in the meeting.

3. **NA** if observer has missed the beginning of the meeting, or if an initial meeting.

45. Care Coordinator directs (or redirects) team to discuss family/child strengths.

Team participants discuss family/child strength(s) at the direction (redirection) of Care Coordinator.

Scoring

1. **Yes** if Care Coordinator directs team to talk about specific strength(s) at the beginning of the meeting or later on in the meeting.

2. **No** if Care Coordinator does not direct team to discuss strength(s) after a substantial amount of time of discussing child deficits.

46. Care Coordinator directs (or redirects) team to develop/revise/update plan of care.

Plan of care (life domain, goals, objectives, or resources/interventions) is revised or updated at the direction (redirection) of Care Coordinator.

Scoring

1. **Yes** if Care Coordinator directs (redirects) team to develop/revise/update plan.

2. **No** if Care Coordinator does not direct (redirect) team to revise/update plan.

47. Care Coordinator summarizes content of the meeting at the conclusion of the meeting.

At the conclusion of meeting Care Coordinator summarizes the content (i.e., what was discussed and agreed upon) of the meeting.

Scoring

1. **Yes** if Care Coordinator verbally summarizes the meeting.
2. **No** if Care Coordinator does not verbally summarize the meeting.

48. Care Coordinator sets next meeting date/time.

At the conclusion of the meeting, Care Coordinator sets next meeting date/time and asks family member if time/date are convenient.

Scoring

1. **Yes** if the Care Coordinator sets date/time for next meeting and if it is convenient for family.
2. **No** if one of above criteria is not satisfied.
3. **NA** if discharge meeting.

Alzheimer's Service Coordination Program (ASCP) Physician Survey

***CCRM Atlas* Measure(s): 9, 10, 11, 12, 13**

Contact Information:

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ALZHEIMER'S SERVICE COORDINATION PROGRAM

PHYSICIAN SURVEY—APRIL1998

Dear Doctor __________:

Thank you for referring _____ patients and their family caregivers to the Service Coordinator for the Alzheimer's Service Coordination Program (ASCP). Please take a few minutes to answer the questions below. Your answers will help us understand how well the ASCP has been working for you.

****

1. After you referred your patients and family caregivers to the ASCP, did you receive a treatment plan listing actions planned, such as reading educational material and using community services, t) help your patients and their families better manage dementia care? (Circle your answer)
    a. Yes, for all patients (even if only one patient referred)
    b. Yes, but only for some patients
    c. Never (SKIP to question 4)

2. Have you ever reviewed or discussed this treatment plan with patients or family caregivers? (Circle your answer)
    a. Yes
    b. No

3. How helpful is this treatment plan as a way for you to discuss dementia care with patients and family caregivers in the office? (Circle)
    a. Very helpful
    b. Somewhat helpful
    c. Not at all helpful

4. Have you had any telephone contact with the ASCP Service Coordinator since referring your patients and their family caregivers to her? (Circle)
    a. Yes
    b. No (SKIP to question 7)

5. How helpful has this telephone contact been in helping you discuss dementia care with your patients and their family caregivers in the office? (Circle)
    a. Very helpful
    b. Somewhat helpful
    c. Not at all helpful

6. Would you like to have more, less, or about the same contact with the ASCP Service Coordinator after you refer a patient and family caregiver to her? (Circle)

   a. More contact
   b. About the same amount of contact
   c. Less contact

7. Has your involvement in the ASCP increased your awareness of the kinds of help available to our patients with dementia and their families? (Circle)

   a. Yes
   b. No

8. Compared to before your involvement in the ASCP, how confident are you now in your ability to discuss dementia care with your patients and families? (Circle)

   a. More confident than before
   b. About the same level of confidence as before
   c. Less confident than before

9. Do you plan to refer more patients and family caregivers to the ASCP in the future? (Circle)

   a. Yes
   b. No

10. In general, how satisfied are you with the ASCP? (Circle)

    a. Very satisfied
    b. Satisfied
    c. Dissatisfied
    d. Very dissatisfied

11. What recommendations would you make to improve the ASCP? Please use the space below

Thank you. Please fax this completed form to

Continuity of Care Practices Survey – Practice Level [CCPS-P]

***CCRM Atlas* Measure(s):** 19, 20

Contact Information:

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Any use of the measure instruments must be accompanied by the following citation: Schaefer, J. A, Cronkite, R. C., & Ingudomnukul, E. (2004). Assessing continuity of care practices in substance use disorder treatment programs. *Journal of Studies on Alcohol*, 65, 513-520. The measure owner requests that users send a copy of any modifications or alterations made to the instrument to Dr. Jeanne A. Schaefer (contact information listed above).

ID# ☐☐☐

CONTINUITY OF CARE PRACTICES SURVEY (CCPS-P)

Your responses to this survey will help us gain a better understanding of the continuity of care practices currently used by clinicians in VA substance use disorder treatment programs.

Please respond to each question. If you do not want to answer a particular question, please circle the number beside it so that we know you did not skip it accidentally.

All questions on this survey concern the program listed below. Please check the information on the attached label and make any necessary corrections

Today's Date: ___________________________________

If you are not the person listed on the label, please provide the following information:

Your Name: _____________________________________

Job Title: _______________________________________

Telephone #: (______)_______–________ext. ________

CCPS-P – Developed by Jeanne Schaefer, PhD
Center for Health Care Evaluation
VA Palo Alto Health Care System
795 Willow Road (152)
Menlo Park, CA 94025

GENERAL PROGRAM AND PATIENT INFORMATION

First, we want to get some general information about patients in your program (including all components). A "**rough ballpark"** estimate of the number or percent of patients is fine.

1. How many unique patients were treated in your program in FY (specify)? **(Patients admitted more than once should be counted only once.)** ☐☐☐☐ **# of patients**

2. What was the total full-time equivalent staff (FTEE) in your program in FY (specify)? **(Include FTEE for positions that are vacant if currently recruiting for them.)** ☐☐☐ **# of FTEE**

3. Approximately what percent of patients in your program in FY (specify) had the following characteristics at intake:

		Percent of patients (0-100%)
A.	Were female?	☐
B.	Were members of racial or ethnic minorities (African American, Hispanic, Asian or Pacific Islander, Native American)?	☐
C.	Were dependent on both alcohol and other drugs?	☐
D.	Had both a substance use disorder and a major psychiatric disorder (excluding PTSD)?	☐
E.	Had a diagnosis of PTSD?	☐

DEFINITIONS – Please read these definitions before continuing with the survey.

The questions that follow ask about the substance use disorder services that your program provided during the **past 3 months**. Please keep these definitions in mind as you answer the questions.

Intensive inpatient/residential programs – For these programs, the **intensive** treatment component of the program means inpatient, residential, or domiciliary services that include more than detoxification and involve a stay of at least 14 days.

Outpatient programs (e.g., day hospital, intensive outpatient clinic) – For these programs, the **intensive** treatment component means that part of the program in which patients receive 3 or more hours of treatment per day for 3 or more days per week.

Continuing outpatient substance use disorder care – This is outpatient care (aftercare) that follows intensive inpatient or outpatient care and provides treatment less than 3 hours per day and less than 3 days per week.

4. In the past 3 months, was continuing outpatient substance use disorder care available **on-site** to patients at your VA facility after they completed intensive substance use disorder treatment? **No** ☐ **Yes** ☐

MAINTAINING CONTACT WITH PATIENTS

5. In the past 3 months, how often did continuing outpatient substance use disorder care staff in your program:	**Never/ rarely 1**	**Some- times 2**	**Fairly often 3**	**Almost always 4**
A. Make reasonable attempts to contact patients within 3 working days of a missed outpatient continuing care substance use disorder appointment?	☐	☐	☐	☐
B. Send appointment reminders to patients prior to their scheduled outpatient continuing care substance use disorder appointments?	☐	☐	☐	☐

6. In the past 3 months, how often did program staff:	**Never/ rarely 1**	**Some- times 2**	**Fairly often 3**	**Almost always 4**
A. Make reasonable attempts to call patients within 14 days of discharge from intensive treatment to find out if patients had contacted the services to which they had been referred?	☐	☐	☐	☐
B. Make reasonable attempts to get discharged patients back into treatment if they were not doing well?	☐	☐	☐	☐

Maintain Contact Subscale – Add scores for 5A-B and 6A-B and subtract the number of responses without missing data, e.g., if one item has missing data, subtract 3 (the number of complete responses);If no responses are missing, subtract 4.

FACILITATING TREATMENT ACROSS LEVELS OF CARE

Here, we ask about practices that aid patients' transition from intensive treatment to continuing outpatient care. Keep in mind that clinicians may rarely use some of these practices. Also, if the continuing outpatient care counselors mentioned in the questions (e.g., 7B, 8-A-E) are the same staff who provided patients' intensive treatment, mark the "Almost always" response.

	Never/ rarely 1	**Some- times 2**	**Fairly often 3**	**Almost always 4**
7. How often in the past 3 months did staff in your program do the following prior to patients' discharge from intensive treatment:				
A. Arrange for patients to meet or talk to the counselor who would be providing them with continuing outpatient substance use disorder care?	☐	☐	☐	☐
B. Arrange for patients to attend continuing care outpatient substance abuse therapy groups during intensive treatment?	☐	☐	☐	☐
C. Arrange for patients to meet or talk to an AA, NA, or CA sponsor in their community?	☐	☐	☐	☐
D. Arrange for patients to attend an AA, NA, or CA meeting in their community during intensive treatment?	☐	☐	☐	☐
E. Secure drug-free or sober living arrangements for patients?	☐	☐	☐	☐
F. Have family members participate in patients' discharge planning for those patients who had contact with their family members?	☐	☐	☐	☐

Connect to Resources Subscale Part 1 – Add 7A-F and subtract the number of responses without missing data, e.g., if one item has missing data, subtract 5, the number of complete responses.

8. How often in the past 3 months did staff in the **intensive** treatment component of your program:	Never/ rarely 1	Some-times 2	Fairly often 3	Almost always 4
A. Speak directly (in person, by phone) with VA outpatient substance use disorder counselors to review patients' discharge summary prior to their first appointment with their counselors?	☐	☐	☐	☐
B. Work with outpatient substance use disorder counselors to jointly develop discharge plans for patients?	☐	☐	☐	☐
C. Notify outpatient substance use disorder counselors when patients who were being referred to them were discharged from intensive treatment?	☐	☐	☐	☐
D. Meet with or contact outpatient substance use disorder counselors at least once a month to review patients' progress and treatment?	☐	☐	☐	☐
E. Contact outpatient substance use disorder counselors within 14 days of patients' discharge from intensive treatment to check if patients were keeping continuing care outpatient substance use disorder appointments?	☐	☐	☐	☐

Coordinate Care Subscale – Add 8A-E and subtract the number of responses without missing data, e.g., if one item has missing data, subtract 4, the number of complete responses.

9. Substance use disorder patients have many coexisting problems, and it's obviously not feasible for staff to address all of the problems of every patient. For each problem listed, please select the **one** referral action that staff in your program typically took prior to patients' discharge from intensive treatment during the past 3 months.

DESCRIPTIONS OF REFERRAL ACTIONS

1. **Patient self-referral –** Left it up to patients to refer themselves to an appropriate program.

2. **Program name or brochure –** Gave patients the name of a program (e.g. a referral slip) or written information (e.g., a program brochure), but did not give them the name of a specific person to contact.

3. **Name & Phone # of contact –** Gave patients the telephone number and name of a specific person to contact at a program.

4. **Set up appointment –** Set up an appointment for patients with a specific staff person at a program.

PATIENT PROBLEM	STAFF ACTION			
	Patient Self-referral 1	Program Name or brochure 2	Name & phone # of contact 3	Set up appointment 4
A. Medical problems	☐	☐	☐	☐
B. Employment problems	☐	☐	☐	☐
C. Housing problems	☐	☐	☐	☐
D. Psychiatric problems (excluding PTSD)	☐	☐	☐	☐
E. PTSD	☐	☐	☐	☐
F. Family Problems	☐	☐	☐	☐

Connect to Resources Part II – Add 9A-F and subtract the number of responses without missing data, e.g., if one item has missing data, subtract 5, the number of complete responses.) To obtain the final Connect to Resources Subscale score add scores for Part I (page 4) and Part II.

DEFINITIONS – Please read these definitions before continuing with Question 10.

Substance use disorder programs vary considerably and program staff define counselor and case manager in many different ways. The definitions we present here may not match your program precisely. Please answer using the definition that best fits your program.

Primary counselor (e.g. a physician, nurse, psychologist, social worker, addiction therapist) – Provides most of the patient's psychological or psychosocial treatment.

Case Manager – Coordinates patient services across different levels of care, but is not the primary psychosocial counselor for patients. For example, the case manager might make sure that patients' needs (e.g., for housing or employment) are addressed and that patients get connected to community resources.

Primary counselor/case manager – Is a staff member who is the primary counselor for patients and also serves as their case manager.

Percent of patients (0-100%)

10. In the past 3 months, approximately what percent of patients in the **intensive component** of your program:

    A. Had the same **primary counselor** during intensive treatment and continuing outpatient substance use disorder care?

    B. Had the same **case manager** during intensive treatment and continuing outpatient substance use disorder care?

    C. Had the same **primary counselor/case manager** during intensive treatment and continuing outpatient substance use disorder care?

Provider Continuity Subscale score Part I – Add 10A-C and divide by the number of responses without missing data, e.g., if one item has missing data, divide by 2, the number of complete responses.

11. In the past 3 months, roughly what percent of patients in your program were assigned to the same counselor, case manager, or addictions treatment team if they relapsed and needed intensive substance use disorder treatment again?

To obtain the final Provider Continuity Subscale score – Add the Part I Provider Continuity Subscale score to the percent from Q11, then divide by 100.

YOU HAVE COMPLETED THIS SURVEY.

THANK YOU VERY MUCH FOR HELPING US BETTER UNDERSTAND TREATMENT PRACTICES IN VA SUBSTANCE USE DISORDER PROGRAMS.

Additional Information For Scoring Subscales With Missing Data.

When scoring the subscales, give the subscale a score if the respondent answers more than half of the items. For subscales with missing data, the sums for the subscale should be weighted by a correction factor which is the ratio of the maximum score if all items are complete over the maximum score for the number of items without missing data. For example, the maximum score for the Coordinate Care subscale is 15 if all 5 items are complete. If a respondent completes 4 items, the maximum score is 12. Consequently, the score for the subscale with one item missing (sum of 4 items) should be weighed by the ratio of 15 over 12, so that the range of values will be the same as it would have been if the respondent had completed all 5 items.

Capacity for Chronic Disease Management in General Practice Research Study Practice Profile Interview – Linkages with External Organisations of Providers (GP-LI)

***CCRM Atlas* Measure(s): 21, 22**

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Centre for General Practice Integration Studies
School of Public Health and Community Medicine
University of New South Wales

Department of General Practice
The University of Adelaide

CAPACITY FOR CHRONIC DISEASE MANAGEMENT IN GENERAL PRACTICE RESEARCH STUDY
PRACTICE PROFILE INTERVIEW
LINKAGES WITH EXTERNAL ORGANISATIONS OR PROVIDERS

Notes to Researchers:

BEFORE THE INTERVIEW

- *Before commencing the interview, check the Pre-visit Questionnaire: Q12 to identify services offered at the practice by attending health professionals as these may be included where appropriate.*

DURING THE INTERVIEW

- *Please follow the suggested wording / script in red*
- *Capture as much information as you can. If you are unsure about the validity of an answer, ask for details.*
- *Where interviewees indicate that they have no more linkages in a category, insert n/a in the free text field and 8 (not applicable) in each associated number field*

AFTER THE INTERVIEW

- *Use F1 Help to code the responses.*
- *Green shaded areas are to be scored after the interview.*

Researcher ID: **Practice ID #:** **Today's Date:**

INTRODUCTION:

"I'd now like to ask you some questions about the linkages and relationships that the practice has with other providers or organisations. This includes services offered at the practice by visiting health professionals.

For the purposes of this part of the interview, consider the situation where you are briefing a new GP who has joined your practice. You're informing the GP about the various links and relationships that the practice has with other providers or organisations.

I'll ask you to describe your practice's clinical links for asthma, type 2 diabetes, and hypertension or ischaemic heart disease. This will be followed by a section on non-clinical links.

While your practice may have links maintained by individual GPs, these questions focus on practice linkages."

Starting with asthma:

---

1. Does your practice have any links with other providers or organisations for **referral or clinical advice** for asthma?

If no go to **Q2**

1 = yes
0 = no
9 = don't know/ unsure/ missing data

Comments:

1.1 1st link:

a. Who is the linkage with? *(If individual providers, ask for profession and initials)*

b. On a scale of 0 – 5, (where **0** is the **lowest** and **5** is the **highest**) rate the effectiveness of the **communication** between the two organisations:

c. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the **quality** of the service provided to your practice:

1.2 2nd link:

a. Who is the linkage with? *(If individual providers, ask for profession and initials)*

b. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the effectiveness of the **communication** between the two organisations:

c. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the **quality** of the service provided to your practice:

1.3 3rd link:

a. Who is the linkage with? *(If individual providers, ask for profession and initials)*

b. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the effectiveness of the **communication** between the two organisations:

c. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the **quality** of the service provided to your practice:

---

2. Continuing with asthma, does the practice provide **shared care or care plans**? ***Prompt only if necessary*** ***Shared care = care delivery in which generalist and specialists work together to meet a patient's needs***	1 = yes 0 = no 9 = don't know / unsure / missing data
If yes, does the practice have links for **shared care or care planning** that you'd tell a new GP about? ***If no***, go to **Q3**	1 = yes 0 = no 8 = not applicable 9 = don't know / unsure / missing data

Comments:

2.1 1st link:

a. Who is the linkage with? *(If individual providers, ask for profession and initials)*

b. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the effectiveness of the **communication** between the two organisations:

c. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the **quality** of the service provided to your practice:

2.2 2nd link:

a. Who is the linkage with? *(If individual providers, ask for profession and initials)*

b. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the effectiveness of the **communication** between the two organisations:

c. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the **quality** of the service provided to your practice:

2.3 3rd link:

a. Who is the linkage with? *(If individual providers, ask for profession and initials)*

b. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the effectiveness of the **communication** between the two organisations:

c. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the **quality** of the service provided to your practice:

---

3. Does your practice have any links to outside providers for **patient education or self help** for asthma? *If no* go to **Q4**	1 = yes 0 = no 9 = don't know / unsure / missing data

Comments:

3.1 1st link:

a. Who is the linkage with? *(If individual providers, ask for profession and initials)*

b. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the effectiveness of the **communication** between the two organisations:

c. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the **quality** of the service provided to your practice:

3.2 2nd link:

a. Who is the linkage with? *(If individual providers, ask for profession and initials)*

b. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the effectiveness of the **communication** between the two organisations:

c. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the **quality** of the service provided to your practice:

3.3 3rd link:

a. Who is the linkage with? *(If individual providers, ask for profession and initials)*

b. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the effectiveness of the **communication** between the two organisations:

c. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the **quality** of the service provided to your practice:

---

4. Does your practice have any links or relationships with outside providers to **improve community awareness of Asthma** or **to improve community access to services or resources?** *If no* go to **Q5**	1 = yes 0 = no 9 = don’t know / unsure / missing data

Comments:

4.1 1st link:

a. Who is the linkage with? *(If individual providers, ask for profession and initials)*

b. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the effectiveness of the **communication** between the two organisations:

c. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the **quality** of the service provided to your practice:

4.2 2nd link:

a. Who is the linkage with? *(If individual providers, ask for profession and initials)*

b. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the effectiveness of the **communication** between the two organisations:

c. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the **quality** of the service provided to your practice:

4.3 3rd link:

a. Who is the linkage with? *(If individual providers, ask for profession and initials)*

b. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the effectiveness of the **communication** between the two organisations:

c. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the **quality** of the service provided to your practice:

---

5. Finally for Asthma, are there any aspects of asthma management that **are needed, but not covered** by your practice's linkages? *If no* go to **Q6**	1 = Yes 0 = No 9 = don't know / unsure / missing data

5.1 If yes, please describe:

1 = if gap in services is identified
0 = no gap identified
8 = not applicable

Moving on to Type 2 Diabetes now.

Again, consider the situation where you're briefing a new GP about the linkages the practice has for clinical purposes.

---

6. Does your practice have any links or relationships with other providers or organisations for **referral or advice** for type 2 Diabetes?

1 = yes
0 = no
9 = don't know / unsure / missing data

(including clinical information and second opinions)

If no go to **Q7**

Comments:

6.1 1st link:

a. Who is the linkage with? *(If individual providers, ask for profession and initials)*

b. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the effectiveness of the **communication** between the two organisations:

c. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the **quality** of the service provided to your practice:

6.2 2nd link:

a. Who is the linkage with? *(If individual providers, ask for profession and initials)*

b. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the effectiveness of the **communication** between the two organisations:

c. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the **quality** of the service provided to your practice:

6.3 3rd link:

a. Who is the linkage with? *(If individual providers, ask for profession and initials)*

b. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the effectiveness of the **communication** between the two organisations:

c. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the **quality** of the service provided to your practice:

---

7. Continuing with Diabetes, does the practice provide **shared care or care plans**? *Prompt only if necessary* *Shared care = care delivery in which generalist and specialists work together to meet a patient's needs*	1 = yes 0 = no 9 = don't know / unsure / missing data
If yes, does the practice have **links** for **shared care or care planning** that you'd tell a new GP about? ***If no***, go to **Q8**	1 = yes 0 = no 8 = not applicable 9 = don't know / unsure / missing data

Comments:

7.1 1st link:

a. Who is the linkage with? *(If individual providers, ask for profession and initials)*

b. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the effectiveness of the **communication** between the two organisations:

c. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the **quality** of the service provided to your practice:

7.2 2nd link:

a. Who is the linkage with? *(If individual providers, ask for profession and initials)*

b. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the effectiveness of the **communication** between the two organisations:

c. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the **quality** of the service provided to your practice:

7.3 3rd link:

a. Who is the linkage with? *(If individual providers, ask for profession and initials)*

b. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the effectiveness of the **communication** between the two organisations:

c. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the **quality** of the service provided to your practice:

---

8. Does your practice have any links to outside providers for **patient education or self help** for type 2 diabetes?

1 = yes
0 = no
9 = don't know / unsure / missing data

If no go to **Q9**

Comments:

8.1 1st link:

a. Who is the linkage with? *(If individual providers, ask for profession and initials)*

b. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the effectiveness of the **communication** between the two organisations:

c. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the **quality** of the service provided to your practice:

8.2 2nd link:

a. Who is the linkage with? *(If individual providers, ask for profession and initials)*

b. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the effectiveness of the **communication** between the two organisations:

c. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the **quality** of the service provided to your practice:

8.3 3rd link:

a. Who is the linkage with? *(If individual providers, ask for profession and initials)*

b. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the **effectiveness** of the **communication** between the two organisations:

c. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the **quality** of the service provided to your practice:

---

9. Finally for type 2 diabetes, does your practice have any links to outside providers to **improve community awareness of Type 2 Diabetes** or **to improve community access to services or resources**?

1 = yes
0 = no
9 = don't know / unsure / missing data

If no go to **Q10**

Comments:

9.1 1st link:

a. Who is the linkage with? *(If individual providers, ask for profession and initials)*

b. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the effectiveness of the **communication** between the two organisations:

c. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the **quality** of the service provided to your practice:

9.2 2nd link:

a. Who is the linkage with? *(If individual providers, ask for profession and initials)*

b. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the effectiveness of the **communication** between the two organisations:

c. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the **quality** of the service provided to your practice:

9.3 3rd link:

a. Who is the linkage with? *(If individual providers, ask for profession and initials)*

b. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the effectiveness of the **communication** between the two organisations:

c. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the **quality** of the service provided to your practice:

---

10. Are there any aspects of type 2 diabetes management **that are needed, but not covered** by your practice's linkages?

If no go to **Q11**

1 = yes
0 = no
9 = don't know / unsure / missing data

10.1 If yes, please describe:

1 = if gap in services is identified
0 = no gap identified
8 = not applicable

"Now I want to ask to you about Hypertension/ Ischaemic Heart Disease.

Again, consider the situation where you're briefing a new GP about the linkages the practice has for clinical purposes."

---

11. Does your practice have any links or relationships with other providers or organisations for **referral or advice** for hypertension or ischaemic heart disease?

1 = yes
0 = no
9 = don't know / unsure / missing data

(including clinical information and second opinions)

If no go to **Q12**

Comments:

11.1 1st link:

a. Who is the linkage with? *(If individual providers, ask for profession and initials)*

b. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the effectiveness of the **communication** between the two organisations:

c. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the **quality** of the service provided to your practice:

11.2 2nd link:

a. Who is the linkage with? *(If individual providers, ask for profession and initials)*

b. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the effectiveness of the **communication** between the two organisations:

c. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the **quality** of the service provided to your practice:

11.3 3rd link:

a. Who is the linkage with? *(If individual providers, ask for profession and initials)*

b. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the effectiveness of the **communication** between the two organisations:

c. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the **quality** of the service provided to your practice:

12. Continuing with Hypertension or IHD, does the practice provide **shared care or care plans**?

1 = yes
0 = no
9 = don't know / unsure / missing data

Prompt only if necessary

Shared care = care delivery in which generalist and specialists work together to meet a patient's needs

If yes, does the practice have links for **shared care or care planning** that you'd tell a new GP about?

1 = yes
0 = no
8 = not applicable
9 = don't know / unsure / missing data

If no, go to **Q13**

Comments:

12.1 1st link:

a. Who is the linkage with? *(If individual providers, ask for profession and initials)*

b. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the effectiveness of the **communication** between the two organisations:

c. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the **quality** of the service provided to your practice:

12.2 2nd link:

a. Who is the linkage with? *(If individual providers, ask for profession and initials)*

b. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the effectiveness of the **communication** between the two organisations:

c. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the **quality** of the service provided to your practice:

12.3 3rd link:

a. Who is the linkage with? *(If individual providers, ask for profession and initials)*

b. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the effectiveness of the **communication** between the two organisations:

c. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the **quality** of the service provided to your practice:

---

13. Does your practice have any links to outside providers for **patient education or self-help** for hypertension or ischaemic heart disease?

1 = yes
0 = no
9 = don't know / unsure / missing data

If no go to **Q14**

Comments:

13.1 1st link:

a. Who is the linkage with? *(If individual providers, ask for profession and initials)*

b. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the effectiveness of the **communication** between the two organisations:

c. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the **quality** of the service provided to your practice:

13.2 2nd link:

a. Who is the linkage with? *(If individual providers, ask for profession and initials)*

b. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the effectiveness of the **communication** between the two organisations:

c. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the **quality** of the service provided to your practice:

13.3 3rd link:

a. Who is the linkage with? *(If individual providers, ask for profession and initials)*

b. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the **effectiveness** of the **communication** between the two organisations:

c. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the **quality** of the service provided to your practice:

---

14. Finally, does your practice have any links to outside providers to **improve community awareness of ischaemic heart disease or hypertension** or to **improve community access to services or resources**?

1 = yes
0 = no
9 = don't know / unsure / missing data

If no go to **Q15**

Comments:

14.1 1st link:

a. Who is the linkage with? *(If individual providers, ask for profession and initials)*

b. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the effectiveness of the **communication** between the two organisations:

c. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the **quality** of the service provided to your practice:

14.2 2nd link:

a. Who is the linkage with? *(If individual providers, ask for profession and initials)*

b. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the effectiveness of the **communication** between the two organisations:

c. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the **quality** of the service provided to your practice:

14.3 3rd link:

a. Who is the linkage with? *(If individual providers, ask for profession and initials)*

b. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the effectiveness of the **communication** between the two organisations:

c. On a scale of 0 – 5, (where 0 is the **lowest** and 5 is the **highest**) rate the **quality** of the service provided to your practice:

---

15. Are there any aspects of hypertension / IHD management **that are needed, but not covered** by your practice's linkages?

If no go to **Q16**

1 = yes
0 = no
9 = don't know / unsure / missing data

15.1 *If yes,* please describe:

1 = if gap in services is identified
0 = no gap identified
8 = not applicable

"Now a general question:"

16. Does the practice have a resource directory of services?

1 = yes
0 = no
9 = don't know / unsure / missing data

If no go to **Q17**

a. If a GP was new to the practice, how helpful would the directory be for making chronic disease referrals? Rate (0 – 5)

b. On a scale of 0 – 5, how complete would he/she find the directory:

Prompt: does it include all the necessary types of specialists etc

c. On a scale of 0 – 5, how up to date would she/he find this directory?

Prompt: are the numbers and addresses correct? Are new services included in the directory?

Note: the practice principal does not need to be present for the remainder of this interview

---

17. Does the practice have any links or relationships with any outside providers/organisations to conduct **quality improvement or research?**

1 = yes
0 = no
9 = don't know / unsure / missing data

Prompt: clinical audits, surveying of patients, etc.

If no go to **Q18**

Comments:

17.1 For each linkage, answer the following questions:

1st link:

a. Who is linkage with?

b. How does this linkage work?

Prompt: Who contacts whom? Is the link for ongoing work or on a casual / ad hoc basis?

c. On a scale of 0 – 5, rate the quality of the service provided to your practice:

17.2 2nd link:

a. Who is linkage with?

b. How does this linkage work?

Prompt: Who contacts whom? Is the link for ongoing work or on a casual / ad hoc basis?

c. On a scale of 0 – 5, rate the quality of the service provided to your practice:

17.3 3rd link:

a. Who is linkage with?

b. How does this linkage work?

Prompt: Who contacts whom? Is the link for ongoing work or on a casual / ad hoc basis?

c. On a scale of 0 – 5, rate the quality of the service provided to your practice:

---

18. If non-GP **staff members require professional development or training**, does the *practice* have a link with any organisations to help in obtaining this?

1 = yes
0 = no
9 = don't know / unsure / missing data

If no go to **Q19**

Comments:

18.1 For each linkage, answer the following questions:

1st link:

a. Who is linkage with?

b. How does this linkage work?

Prompt: Who contacts whom? Is the link for ongoing work or on a casual / ad hoc basis?

c. On a scale of 0 – 5, rate the quality of the service provided to your practice:

18.2 2nd link:

a. Who is linkage with?

b. How does this linkage work?

Prompt: Who contacts whom? Is the link for ongoing work or on a casual / ad hoc basis?

c. On a scale of 0 – 5, rate the quality of the service provided to your practice:

18.3 3rd link:

a. Who is linkage with?

b. How does this linkage work?

Prompt: Who contacts whom? Is the link for ongoing work or on a casual / ad hoc basis?

c. On a scale of 0 – 5, rate the quality of the service provided to your practice:

---

19. Does the *practice* have links or relationships with individuals or organisations that provide **technical support** (such as IT or equipment assistance)?

1 = yes
0 = no
9 = don't know / unsure / missing data

If no go to **Q20**

Comments:

19.1 For each linkage, answer the following questions:

1st link:

a. Who is linkage with?

b. How does this linkage work?

Prompt: Who contacts whom? Is the link for ongoing work or on a casual / ad hoc basis?

c. On a scale of 0 – 5, rate the quality of the service provided to your practice:

19.2 2nd link:

a. Who is linkage with?

b. How does this linkage work?

Prompt: Who contacts whom? Is the link for ongoing work or on a casual / ad hoc basis?

c. On a scale of 0 – 5, rate the quality of the service provided to your practice:

19.3 3rd link:

a. Who is linkage with?

b. How does this linkage work?

Prompt: Who contacts whom? Is the link for ongoing work or on a casual / ad hoc basis?

c. On a scale of 0 – 5, rate the quality of the service provided to your practice:

---

20. Does the *practice* have links or relationships with individuals or organisations that **provide practice staff** to expand the range of services offered by the practice?

1 = yes
0 = no
9 = don't know / unsure / missing data

If no go to **Q21**

Comments:

20.1 For each linkage, answer the following questions:

1st link:

a. Who is linkage with?

b. How does this linkage work?

Prompt: Who contacts whom? Is the link for ongoing work or on a casual / ad hoc basis?

c. On a scale of 0 – 5, rate the quality of the service provided to your practice:

20.2 2nd link:

a. Who is linkage with?

b. How does this linkage work?

Prompt: Who contacts whom? Is the link for ongoing work or on a casual / ad hoc basis?

c. On a scale of 0 – 5, rate the quality of the service provided to your practice:

20.3 3rd link:

a. Who is linkage with?

b. How does this linkage work?

Prompt: Who contacts whom? Is the link for ongoing work or on a casual / ad hoc basis?

c. On a scale of 0 – 5, rate the quality of the service provided to your practice:

---

21. Does the *practice* have links or relationships with individuals or organisations that provide **business support (accounting, strategic planning etc)?**

1 = yes
0 = no
9 = don't know / unsure / missing data

If no go to **Q22**

Comments:

21.1 For each linkage, answer the following questions:

1st link:

a. Who is linkage with?

b. How does this linkage work?

Prompt: Who contacts whom? Is the link for ongoing work or on a casual / ad hoc basis?

c. On a scale of 0 – 5, rate the quality of the service provided to your practice:

21.2 2nd link:

a. Who is linkage with?

b. How does this linkage work?

Prompt: Who contacts whom? Is the link for ongoing work or on a casual / ad hoc basis?

c. On a scale of 0 – 5, rate the quality of the service provided to your practice:

21.3 3rd link:

a. Who is linkage with?

b. How does this linkage work?

Prompt: Who contacts whom? Is the link for ongoing work or on a casual / ad hoc basis?

c. On a scale of 0 – 5, rate the quality of the service provided to your practice:

---

22. Does the *practice* have links or relationships with individuals or organisations with which **resources, equipment, or services are shared?** *(eg share practice manager, nurse, computer templates)*

1 = yes
0 = no
9 = don't know / unsure / missing data

If no go to **Q23**

Comments:

22.1 For each linkage, answer the following questions:

1st link:

a. Who is linkage with?

b. How does this linkage work?

Prompt: Who contacts whom? Is the link for ongoing work or on a casual / ad hoc basis?

c. On a scale of 0 – 5, rate the quality of the service provided to your practice:

22.2 2nd link:

a. Who is linkage with?

b. How does this linkage work?

Prompt: Who contacts whom? Is the link for ongoing work or on a casual / ad hoc basis?

c. On a scale of 0 – 5, rate the quality of the service provided to your practice:

22.3 3rd link:

a. Who is linkage with?

b. How does this linkage work?

Prompt: Who contacts whom? Is the link for ongoing work or on a casual / ad hoc basis?

c. On a scale of 0 – 5, rate the quality of the service provided to your practice:

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23. Does the *practice* have any other links or relationships with **organisations, professional bodies or networks** for the benefit of the practice?

1 = yes
0 = no
9 = don't know / unsure / missing data

Comments:

23.1 For each linkage, answer the following questions:

1st link:

a. Who is linkage with?

b. How does this linkage work?

Prompt: Who contacts whom? Is the link for ongoing work or on a casual / ad hoc basis?

c. On a scale of 0 – 5, rate the quality of the service provided to your practice:

23.2 2nd link:

a. Who is linkage with?

b. How does this linkage work?

Prompt: Who contacts whom? Is the link for ongoing work or on a casual / ad hoc basis?

c. On a scale of 0 – 5, rate the quality of the service provided to your practice:

23.3 3rd link:

a. Who is linkage with?

b. How does this linkage work?

Prompt: Who contacts whom? Is the link for ongoing work or on a casual / ad hoc basis?

c. On a scale of 0 – 5, rate the quality of the service provided to your practice:

That brings us to the end of this section of the interview. Thank you for your input.

Researcher comment:

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The Eden Alternative
Domains of Well-Being™

EDEN
ALTERNATIVE®

Revolutionizing the Experience of Home
by Bringing Well-Being to Life

THE EDEN ALTERNATIVE DOMAINS OF WELL-BEING™
Revolutionizing the Experience of Home by Bringing Well-Being to Life:

> "Well-being is a much larger idea than either quality of life or customer satisfaction. It is based on a holistic understanding of human needs and capacities. Well-being is elusive, highly subjective, and the most valuable of all human possessions."
>
> Dr. William Thomas, *What Are Old People For?*

A question that has long-challenged those committed to changing the culture of care is:

What makes life worth living, and how do we measure it?

Pioneers of culture change contend that aging and living with unique health challenges need not be about decline and despair, but instead, a chance to joyously soar to new heights of human growth and awareness. We hold lofty goals for how we care for each other, seeking environments across the continuum of care that foster community rather than loneliness, meaningful activity rather than boredom, and self-reliance rather than helplessness.

The traditional model of health care has much lower goals — simply to mitigate decline. And despite the best efforts of thousands of highly skilled professionals and billions of dollars in government support, the system is failing us all.

Elders and others accepting support[1] often feel as though they need to give up their autonomy in order to receive the assistance they need. Family members agonize over the prospect of "placing" loved ones in long-term care environments. Employees, who give their hearts and souls to caring for Elders and other individuals accepting support, experience the frustration of the broken system. Boards of Directors struggle to keep the doors open in the face of rising costs and inadequate reimbursement. A flood of litigation and losses overwhelms liability insurance providers. Service providers struggle to provide quality care and services in a tight market where competing demands often trump any efforts to reframe the priorities defined by the system and put the person first.

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[1] *The Eden Alternative defines an Elder as someone who by virtue of life experience is here to teach us how to live. Even though this definition implies that one needn't be chronologically older to be an Elder, we assume that not everyone will relate to the term "Elder" as the most appropriate identifier, regardless of this definition. We encourage you to "fill in the blank," as needed, wherever you see the phrase "Elder or individual accepting support." Apart from how you choose to identify the individual accepting support, this person should be seen as an active partner in his or her own care.*

The Culture Change Movement Facilitates Well-Being…

"Culture change" is the common name for a global initiative focused on transforming care, as we know it, for Elders and individuals living with different physical, developmental, intellectual, and psychological abilities. It advocates for a shift from institutional models of care to person-directed values and practices that put the person first. Person-directed care is structured around the unique needs, preferences, and desires of the individual in question. Through this approach, decisions and actions around care honor the voices and choices of care recipients and those working most closely with them.

The ultimate goal of culture change is well-being for all — all care partners (the Elder or individual accepting support, employees, family members, and volunteers), the organization, and ultimately the community. The Eden Alternative promotes the concept of care partnership, which affirms that care is a two-way street, focused on ensuring the growth and well-being of everyone involved in the care relationship. It acknowledges that the quality of our relationships is the key to our success, and that care and well-being is for everyone, not just the individuals receiving treatment or services.

While the person-directed model of care challenges us to change our attitudes, beliefs, and values, it also redefines how we measure the quality of outcomes — a need growing increasingly urgent, as more and more organizations begin the culture change journey. The institutional model has well-defined measurements, focused mostly around quality of care issues, with outcomes posted on our government's website for all to see. If used properly, they are effective for determining if an Elder is receiving appropriate physical care, but they fail to measure the nuances of a life worth living. To address this deficit, we need to define a new way to articulate and define our success.

So, what is quality of life? How do we define genuine caring?

As human beings, we are inclined to pay more attention to the negative rather than the positive, to see the limitations rather than the possibilities. Our language and our societal perceptions reinforce the view that aging and/or living with physical, developmental, intellectual, or psychological challenges equals decline or disability. Well-being, as a frame of reference, requires us to focus on the strengths, possibilities, dreams, and goals of each individual. Doing so, we define quality of life in terms of what each individual can do and what they have to *offer* their communities.

Many organizations believe they are "living culture change," when in reality, they are just polishing the brass and shining up the glass. This kind of window dressing does not deeply impact the lives of the people who live and work in the home, wherever home may be. How will we know the difference? How will family members discern organizations committed to person-directed care from other options? How will professional care partners seeking employment know if they've chosen the right place to work? How will our government measure quality in the new model of care? How will providers be reimbursed? The answer to these questions relies on the development of a simple, well-articulated frame of reference that drives home what it is we all want for ourselves and for our loved ones: well-being.

The Eden Alternative recognizes the importance of measuring well-being among all members of the care partner team. It is our contention that in a true community, we can only experience true well-being, if those surrounding us are also.

Well-being can be simply defined as "a contented state of being." Satisfaction, wellness, and happiness are concepts that are often used interchangeably with well-being. However, satisfaction is based on expectations. If others don't meet them, we are not satisfied. Wellness implies healthiness, which may peak and decline over time. Happiness, too, is a human emotion that comes and goes. In contrast, well-being evolves and develops over a life time, deepening as we grow into our full potential as human beings.

Well-being is the path to a life worth living. It is the ultimate outcome of a human life. It leads us to ask the following questions: What are the components of well-being? What do we need to experience contentment? Through a collaborative effort involving a task force of culture change specialists, The Eden Alternative has identified seven primary Domains of Well-being: identity, growth, autonomy, security, connectedness, meaning, and joy.

The Eden Alternative Domains of Well-Being

IDENTITY – being well-known; having personhood; individuality; wholeness; having a history

Nothing exists without identity. The healthcare system, as it exists today, strips away individuals' identities, leaving them virtually unknown and vulnerable. The medical model identifies people by their job title alone, their disease process, what they need assistance with, or how their food is prepared and served. If you need increased assistance with daily life, you find yourself compartmentalized and grouped with others in a similar situation. Your identity is now tied to others.

Becoming well-known is a hallmark value of The Eden Alternative. Part of knowing each other deeply involves acknowledging our strengths and what we each have to offer. How we bring forth these strengths each day is a powerful way to celebrate each other's unique individuality.

In her research on institutionalized Elders, Judith Carboni, RN, MSN, CS notes:

> "Elderly residents in nursing homes face non-personhood: identity becomes murky because they no longer have a special bond with a place that held a significant, personal meaning. Informants demonstrated a pervasive sense of uprootedness and non-belonging, as well as confused feelings about self and identity. What is significant in this feeling of uprootedness is its finale. In both instances, it appeared that the roots that fed each informant's identity and provided nurturance were more than merely pulled up; it seemed that the roots were actually severed. For example, how can one recover the roots of one's house if it is sold,

> how can one identify with a place that is no longer there? When possessions are dispersed among relatives or sold, they are no longer available to the individual for interaction and meaning; the relationship with objects and their memories have become severed."
>
> Carboni, Judith D., *Homelessness Among The Institutionalized Elderly*,
> *Journal of Gerontological Nursing*, July 1990.

Identity is socially constructed. One's identity, history, life, and sense of self are essential components of well-being. Without this, individuals "cease to exist."

In our health care system, we use care plans as a way to establish one's identity in terms of what assistance they need and the deficits they live with. Defining care needs in terms of diagnosis or disease homogenizes individual experience in favor of a group identity. When we use well-being as our frame of reference, the care plan becomes very individualized, focusing on strengths, preferences, goals, and growth. Now that we have a full picture of an individual's identity, we know how to partner with her to highlight and strengthen her sense of individuality. This is true for everyone involved in the care relationship: the Elders and other individuals accepting support, employees, and family members.

Bringing identity forward:

- *How do welcoming rituals bring forth the identity of the care partner (Elder or individual accepting support, employee, or family member)?*
- *How do conversations among the care partner team members reflect a "knowing" of the individual's identity?*
- *How do our care partners help people continue to become well-known to one another?*
- *In written language, how is each individual's identity revealed?*
- *How are individual strengths applied to affirming each person's unique identity?*

GROWTH – development; enrichment; unfolding; expanding; evolving

The institutional model of care centers on mitigating decline and disability. The person-directed model offers a radically different belief.

Longevity gives forth its own promise and potential. From the employee care partner's perspective, the institutional model offers little opportunity for personal growth in what are often considered "dead-end jobs." In a person-directed model of care, Elders and their care partners have every opportunity to learn and grow. The opposite of growth is death — physical and spiritual. Individuals living with frailty continue to grow and teach us how to be human beings in a caring community. Everyone has the potential to be a "growth partner" to someone else.

We thrive when we have good medical treatment and appropriate care. Someone can benefit from several aspects of well-being, but may have a health condition that is out of control which significantly inhibits growth. Quality care enables growth, and medical treatment effectively serves this process. Care (helping another to grow) and medical treatment are skillful partners. Care for the individual comes first and foremost.

Bringing growth forward:

- *How are the strengths, dreams and goals of individuals captured and shared in the community?*
- *How does the care partner team work together to help one another to grow based on individual strengths and goals?*
- *What opportunities are all care partners given to be exposed to new life experiences and knowledge?*

AUTONOMY – liberty; self-governance; self-determination; immunity from the arbitrary exercise of authority; choice; freedom

Simply put, to be autonomous is to be one's own person … to be respected for one's ability to decide for oneself, control one's life and absorb the costs and benefits of one's own choices. Lacking autonomy, is a condition which allows or invites sympathy, pity or invasive paternalism.

The key to grasping the depth of autonomy is balance. The right to folly is an important part of autonomy. If people are only able to choose between courses of action that are "good for them" or "pre-selected" then the true dimension of autonomy is greatly diminished. No one, with very few exceptions, has complete autonomy. It is an optimized concept, not a maximized concept.

Top-down organizational structures squeeze the life out of autonomy for Elders and others accepting support and the care partners closest to them. This eliminates the possibility of creative approaches by the employee care partners who are most familiar with Elders as individuals and have the most frequent and meaningful interactions. As a result, those who are likely to have the strongest impact on an individual's daily life experience are the least involved in important decision-making.

Principle Four of the Eden Alternative Philosophy reminds us that the opportunity to give as well as receive is the antidote to helplessness. People who identify as caregivers sometimes perceive good "caregiving" as doing everything possible for another individual. However, this well-meaning generosity can lead to learned helplessness and diminish individual choice. This imbalance of care ultimately destroys autonomy for everyone involved in the care relationship. In contrast, the concept of care partnership reminds us that care is not a one-way street, that opportunities to give as well as receive are abundant and available to everyone in the care partner team, so-called "caregivers" and "care receivers" alike. Care partnership, as a way of relating to each other, helps us optimize choice.

Bringing autonomy forward:

- *When engaging care partners, do leaders seek input and ideas or truly empower them to take an active role in daily decision-making?*
- *What are some ways individual choice is optimized in the community?*
- *How do care partners uncover assumptions that may cause us to limit choices for one another?*
- *How does the care partner team handle situations when poorer choices are made?*
- *Are mistakes an opportunity for punishment, or limitation, or an opportunity for growth?*

SECURITY – freedom from doubt, anxiety, or fear; safe, certain, assured; having privacy, dignity, and respect.

Abraham Maslow theorized that human beings are motivated by a hierarchy of needs, and that certain lower needs must be satisfied before higher needs can be fulfilled. For example, safety needs — the security of home and family, freedom from fear and anxiety — must be satisfied before we can grow toward self-actualization.

In his speech on the four freedoms, Franklin Delano Roosevelt touched on the right of human beings everywhere to feel secure in their ability to express themselves freely, to define their own unique relationship with spirit, to feel financially stable, and to be free from fear.

Security also expands beyond the basic need for safety to also include right to privacy, dignity and respect. A person receiving support services often finds their space becoming public space, forcing her into involuntary, intimate situations with strangers.

Another aspect of security involves ensuring that our commitment to safety doesn't infringe on someone's rights and choices. This is where Autonomy and Security are closely related domains. Eden Alternative Co-founder Dr. Bill Thomas reminds us to consider "surplus safety" when optimizing, rather than maximizing, security for another. Our healthcare system is risk averse. Once an individual relies on the support of others on the care partner team, they find their safety maximized and opportunities to take risk diminished, if not removed entirely. To take away all risk and chances to make mistakes is to take away the right to be human. Maximizing safety actually creates insecurity. While safety is important, there is a range of risk tolerance. Optimizing safety with the individual, based on their risk tolerance, creates security.

Bringing security forward:

- *How does the care partner team uncover and address anxieties and fears that members of the team possess (Elders and individuals accepting support, employees, family members)?*
- *How do care partners protect the dignity and privacy of individuals in this community?*
- *What does respect for one another look like on the care partner team?*
- *How comfortable are care partners in their physical space and with those living or working in that space?*
- *In what ways is the care partner team optimizing the safety of its members?*

CONNECTEDNESS – state of being connected; alive; belonging; engaged; involved; not detached; connected to the past, present and future; connected to personal possessions; connected to place; connected to nature.

> "No man is an island, entire of itself: every man is a piece of the continent."
>
> — John Donne

The idea John Donne brings forth in this meditation is not an unusual one — this idea of interconnectedness. Studies show physical and emotional benefits to staying connected with loved ones and with one's environment. Connectedness is more than being surrounded by people who are friendly or skilled in customer service. It is about being in meaningful, and sometimes deep, relationships with others. It is about being a part of something that is bigger than ourselves. It is about being surrounding by things that have personal meaning for us throughout our homes. It means knowing our history and looking forward to our future.

During our lives many connections can be lost — we retire, spouses and friends die, children, friends and neighbors move away, we are home-bound and don't get out as much — all of these place us at high-risk for feeling disconnected. Individuals can become disconnected from the past, by loss of familiar relationships, places and personal possessions, and from the future by loss of hopes and dreams. Thus, the present reality becomes endless days of loneliness, helplessness, and boredom. As this seeps into their spirits, many disconnect completely from the physical and social environment.

A person-directed model seeks to reconnect Elders or individuals accepting support and their care partners with the past, present, and future, with their environment and with hope and dreams. Care partner relationship consistency is the beginning of this reconnection. Creating a home space that is filled with meaningful items, and not medical trappings, continues the connections. Restoring relationships and making peace with one's life can be another way to foster connectedness. The possibilities are endless as we get to know each other's stories.

Bringing connectedness forward:

- *How are members of the care partner team connecting with one another regularly?*
- *How are meaningful connections in the lives of care partners identified and shared?*
- *What actions are the care partner team members taking to help all team members continue or build connectedness?*
- *What role does a connection with the larger living world play in the individual's life and how is the care partner team developing that connection?*

MEANING – significance; heart; hope; import; value; purpose; reflection; sacred

The medical model of care strips away meaning in many different ways. The physical environment becomes meaningless for anyone except the decorator who designed it or healthcare professionals who access it. The sacred work of care partnering is reduced to a series of tasks and procedures delineated in the interdisciplinary care plan. The rhythm of daily life becomes repetitive and numbing, holds no meaning and inspires little motivation for the individual.

A person-directed approach infuses meaning into every corner, every act and every relationship. This way, all care partners share in a life worth living. Simple pleasures are brought to life for all. The rhythm of daily life is affirming and nurturing, drawing people together in meaningful ways. Meaning is generated because of the caring relationships we have nurtured with one another.

Creating meaning takes a lifetime of effort. Meaning thrives and grows in moments of time. It is more than fulfilling a life's wish. It is woven into our emotions, our feelings, and our need to be needed. Each individual and each community experiences meaning in different ways. Meaning sometimes arises out of other life events; trying to rationalize trials and successes. Often meaning comes from the very act of searching for it. Food and shelter can be withheld, but meaning is something others cannot deny us. Regardless of our life situation, as humans we are always seeking meaning.

Bringing meaning forward:

- *How are care partners learning each other's stories of times when they find meaning in their lives?*
- *How is time for reflection and celebration woven into care partners' lives?*
- *How are individual's goals honored and achieved in meaningful ways?*

JOY – happiness; pleasure; delight; contentment; enjoyment

> "Joy seems to me a step beyond happiness – happiness is a sort of atmosphere you can live in sometimes when you're lucky. Joy is a light that fills you with hope and faith and love."
>
> — Adela Rogers St. Johns

Joy is a short, simple word that describes the best, most elusive dimensions of human experience. While people often identify joy with a response to a specific experience (for example the birth of a child) these moments are actually more accurately understood in terms of "happiness." Joy is both deeper and more encompassing than happiness.

One of the best ways to understand "joy" and the role this emotion can play in our experience of well-being is to become aware of how often it sneaks up on us. Moments of joy often catch us by surprise. These joyful moments cannot be scheduled, structured, or commanded into existence. They can only emerge from the moment. No one can say "I'm going to experience joy at 2:30 this afternoon." Efforts to intentionally create joy for others are doomed to failure. The best soil for joyful moments is always found in places where relationships are deep, rich, and intensely meaningful. It is through the relationships we have with one another that we can discover ways to recognize and celebrate moments of joy when they occur.

Bringing joy forward:

- *Share stories about joyful moments in life.*
- *How can joyful energy enrich the lives of members of the care partner team?*
- *How does each member of the care partner team define "joy?"*
- *How do care partners express the joy they experience with one another?*

How to use the Eden Alternative Domains of Well-Being

We recommend weaving the Domains of Well-Being deeply into the systems and practices used to support individuals wherever they live. Here are some examples:

- Growth plans (care plans)
- Problem solving
- Developing new systems
- Guide personal, organizational, and physical transformation
- Woven into education, policies and procedures, handbooks
- Welcoming new care partners
- Evaluating and developing new systems
- Team development
- Leadership development
- Assessment of the organization
- Assessment of individual neighborhoods or households
- Assessment of the care partner team members

A grant funded project focused on identification of these seven Domains of Well-being was funded by The Eden Alternative and involved the contributions of the following individuals: William Thomas, MD; Nancy Fox; LaVrene Norton, MSW; Arthur W. Rashap, JD, LLM; Joe Angelelli, PhD; Vivian Telllis-Nyak, PhD; Mary Tellis-Nyak, PhD; Leslie A. Grant, PhD; Sandy Ransom, RN, MSHP; Susan Dean, MSW; Suellen Beatty, BSN, MSN; Dawn Brostoski, RN.

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