It Takes A Village (TOC)

Coordination and palliative care

Pointers and Tips

Stories

It Takes A Village (TOC) > Things to do first

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It Takes A Village (TOC) > Introduction

Community coalitions can be an effective way to engage diverse stakeholders in achieving common goals. Establishing such coalitions to address problems in care transitions is likely to be an essential tool for ensuring that such transitions become routinely good. Shortcomings in transitions today reflect larger, systemic problems that can best be addressed by community organizations working together. Indeed, no single organization will be able to resolve the broader issues, or work on its own to improve care transitions. It will truly take a village to make transitions safe, effective, and routine.

Many organizations around the country are looking to build coalitions that focus on care transitions. For many, similar experiences building community connections will enable them to establish and lead such coalitions. But many others will need guidance and support for learning the basics of coalition building, and for understanding issues specific to care transitions.

This workbook aims to play that role, offering community leaders ideas and pointers for how to get started - and how to get going. It provides an overview of coalition building, ranging from recruiting partners to resolving governance. It describes what to consider when setting priorities for the work. Much of the text is devoted to issues of measurement - how will coalitions know that their work is improving patient care and experience? This guide explains how to use measurement to advance the coalition's goals, how to find good data sources, and how to decide on what to measure. It provides very specific information on fixing care transitions, including how to fix the hospital discharge process and how to target rehospitalization. Because care transitions have a major effect on very sick and vulnerable patients and families, this guide also includes ideas for how coalitions can coordinate their efforts with palliative care programs and services.

Community coalitions have proven effective at addressing diverse public health issues, from improving maternal and child health to creating healthier environments. Coaltiions are defined by their focus on a particular issue, by their willingness to collaborate, and by their ability to bring a range of resources and perspectives to problem-solving. This guide offers a starting point - we hope you find it compelling and useful.

We'd like to hear about your experiences - what works for you and what doesn't, where are your successes and what have been your challenges. Please email us at info@medicaring.org, or follow our blog at www.medicaring.org/ct/.

It Takes A Village (TOC) > Things to do first > What to fix

What might you aim to fix? You may have a clear sense of what serious problems your community faces and what kinds of responses are possible - or you may generally know that there are substantial problems and many opportunities, and be looking for guidance as to how to get started. Considering some common challenges and your initial answers may give your group more clarity and commitment, especially if you think through a list of common issues that communities often tackle on their way to success.

Things to know about your community -- overview

1. What issues are already visible and have key people or the citizens generally "riled up?"
2. Who has stepped forward as a potential leader? Who could? How effective?
3. What problems really affect setting priorities for health and health care in your area?

4. What boundaries can work to define your locality?
5. Who might work with you, and what would it take to get them on board? (See: Quick starts and strategic plans and Governance of community coalitions)
6. How could you build a voluntary organization that can learn, make decisions, and implement actions - and endure? (See: Governance of community coalitions and Ostrom's model)
7. What organizations has your locality developed and supported to do work in the public interest? Can you build on their work?

You probably would do well to consider and reconsider these issues at each phase of your work. The responses will change, and the degree to which your team can answer them will generally improve.

Targets for improvement in local reform - the ones with promising track records!

1. Hospital and nursing home discharges - and transitions between settings in general.
2. Prevention - including better peri-natal outcomes, self-care support for chronic conditions, and support of elderly or disabled persons in the community (www.cdc.gov, and search for a range of prevention topics).
3. Control of costs or costly infrastructure (e.g., limiting demand for new hospital beds).
4. More reliable care for people living with advanced illness.

It takes a village (TOC) > Things to do first > Get Started

How can you get started?

You already are started - you are at least ready to be reading on this website! Remember that making changes nationwide depends upon learners continuing to contribute - so make a note to contribute as your initiatives progress by making a comment at medicaring.org/ct!

How far along are you? Do you have a mandate or a group that might make a working team? Do you have a motivating issue? Addressing costs is a necessity in the process of providing health care.Usually, you will find that the most difficult thing is to forge the will to make changes happen. This sounds deceptively easy - but moving people to actually do something differently today, rather than following the familiar and dysfunctional patterns that have come to be accepted, is very hard to do. Even having a lot of people willing to complain is not quite the same as convincing even those same people to try out something new. You will have to attend to the ongoing issue of generating and sustaining the will to make improvement happen.

What helps?

- Data helps - facts about the experience of people facing your community's systems, or about the costs and effectiveness compared with other areas. Sections of this web site to explore are common data sources, measures of patient experience, measures of cost, and general measures of population health.
- Good stories are essential - much about health and health care is a bit obscure to most people until it personally touches them, and stories are how people learn at both the cognitive and emotional levels. See examples in the Stories section.
- Leadership is essential - someone (usually a group) has to embody the vision, take some risks, forge coalitions, exercise political pressure, and otherwise anchor the work.
- Building on local issues helps. Something is probably already brewing, so build on it! If lots of elderly persons are bouncing back into hospitals after discharge, or lots of children are not getting immunized, then ask yourself whether you can generate outrage that might move action about that.
- Think ahead - always consider where you want to be in a couple of years. You might consider how to build a good community coalition. Relevant topics to explore are governance of community coalitions, the case for local reform, and building coalitions.
- Testing in small ways helps get things started (once good ideas are proven to work your commitment committed to expanding to more people or places will be easier).

What is most important is starting the process! Simply begin. Find something that can get underway. Test it out in the most auspicious setting. Learn from the test. Bring people into the endeavor. Build enthusiasm. Notice that things are changing, even if just for a few people at first.

Everything else can be backfilled with later work.

It takes a village (TOC) > Things to do first > Quick starts and strategic plans

One of the many tensions that system improvement agents have is to balance building for long-term effectiveness with getting improvement done now! While there is no easy metric for a good balance, it is quite clear that community efforts fail by focusing only on one or the other. Efforts that carefully build coalitions, funding, and staff before starting to do the work usually fail to generate enthusiasm or growth and become comfortable with endless planning rather than implementation. Efforts that whip up good work in short time without building any infrastructure or broader vision likewise usually fail because when the first problematic issues are dealt with, they have no reason or means to keep going. Don't let your work trend toward one or the other pole!

Getting to quick starts requires facility with testing. Rather than spending a lot of time on planning a grand program, find some setting where a few people could try out a different approach. Find a few patients one afternoon to try out improved advance care planning, find a few patients undergoing hospital discharge and test one of the published methods to achieve better transitions, or find a group of young mothers at risk and try out one of the proven strategies to improve childhood nutrition. Testing a new approach in a carefully observed situation is less threatening than implementing a program that takes a lot of resources and involves a lot of people. But it does require having a plan in place as to how to learn, who will learn, and how to make improvement spread and be sustained.

Building strategies for sustainability requires thinking through the question of how to make change "inevitable" as a political matter. Who has an interest in things being better? Some are surprised to find that businesses have become major pressure points for controlling health care costs - after all, health care is a business! But health care costs are making it more and more difficult to compete in an increasingly international marketplace. Sometimes allies arise from public-minded leadership; but mostly, committed collaborators have a strong self-interest that is better served by cooperation than by competition. This is a delicate balance. Often "enlightened self-interest" depends upon enough of the participants cooperating to make it better for all - so a community of trust becomes important. If every medical care provider believes that many others will not cooperate in a better discharge process, then no one will cooperate because doing so hurts each provider's income in the short run. If, on the other hand, most medical care providers believe that most others are going to play by group rules that improve discharge management and limit harm to patients, then that provider is going to go along with a modest short term loss of income in order to serve patients better, to feel better about his or her work, and to avoid penalties in the longer run. This is illustrated in the work of Elinor Ostrom.

It takes a village (TOC) > Things to do first > Overall goals

In the US, working to improve local health care systems is underdeveloped. See our sections titled Why local reform and Ostrom's model. There is not a substantial body of work that can provide strong guidance as to what works best (indeed, that is why you will want to add your experiences to this website - to help build wisdom faster!). Nevertheless, you can readily build a strong vision of what a really good care system would do.

The Institute of Medicine has laid out the basics of what a good care system would do (IOM, Crossing the Quality Chasm, National Academy Press, Washington, DC; 2001, http://www.nap.edu/openbook.php?isbn=0309072808):

- Safe
- Effective
- Timely
- Efficient
- Equitable
- Patient-centered

The call to be safe entails preventing harm caused by health care, such as medication errors, hospital-acquired infections, or failure to follow advance care plans. Health care obviously needs to be effective in improving health, which usually means that the diagnosis and treatment follows best available guidelines and evidence. Services that are delayed past the optimal timing are not only a special cause of harm and reduced effectiveness but also are frustrating to patients and families, so timeliness is an important goal. Most health care actually comes from shared community funds, whether through government programs or large insurance pools, so the community has a strong interest in avoiding waste and inefficiency. More than many other products and services, the society feels that all people should have the opportunity to live long and healthy lives, and thus we seek to have no groups who get limited access or second-rate services. And finally, health care is about suffering people whose dignity, autonomy, and personal preferences matter; so health care is excellent only when it adapts to meet the patient as an individual.

This high-level set of aims anchors much of the vision of excellence in health care, but another formulation provides a different perspective on community health. The "Triple Aim" work of the Institute for Healthcare Improvement sets forth three broader aims for a community working toward an ideal (see: http://www.ihi.org/IHI/Programs/StrategicInitiatives/TripleAim.htm).

1. First, a community wants to have each person to experience good health care, along the lines of the six IOM characteristics above.
2. Second, a community wants to have their population experiencing improving health overall, which requires attention to health care and to many other determinants of health such as diet and exercise and conditions of work.
3. Third, a community wants to have these good things without crippling expenses, so they want to do better with current resources and avoid rises in per capita costs.

A local coalition might consider these characteristics from time to time and think through whether there are important targets for improvement among some of the six IOM characteristics of quality health care, or among the three joint aims of the Triple Aim, that their community really should pursue. And if the coalition states a mission, these sources are useful when the team wants to articulate their mission.

It takes a village (TOC) > Things to do first > Health and health care

Some readers of this website may get tangled in the distinction between "health" and "health care." Population health is the overall well-being, productivity, and enjoyment of life of a group of people, and the services that doctors and hospitals provide are only a small part of the determinants of the health of a community. "Health care," on the other hand, are the services provided to prevent, diagnose, and treat illness. This includes all of "medical" care and other professional services such as immunization, dental care, long-term care, and rehabilitation.

Sometimes "health care" is split into "social services" (such as Meals on Wheels, housing support, homemaker assistance) and "medical services" (such as doctors and hospitals). In this website, we have generally combined these. In general, when Americans speak of "health reform,' we really mean "health care reform" (or at least "health care financing reform"); and we are not usually focused upon community jobs, housing, and food supplies as major determinants of health. In this website, we have tried to be careful to use "health" to indicate overall population health, generally as measured both by objective findings like rates of illness and life expectancy and by subjective self-report of health. Similarly, we have used "health care" to indicate professional, paid services provided to prevent, diagnose, or treat illness. The status of caregiving by family and friends (sometimes called "informal caregiving" to distinguish it from paid services from a business) is a major and largely under-appreciated part of "health care" and it turns out to be important for the "health" of populations living with disabilities and illnesses. However, usually estimates of the costs or service array in a community do not include estimates of the contribution of unpaid kith and kin.

It takes a village (TOC) > Creating coalitions

- Governance of community coalitions
- Building coalitions
- Community-ness
- Ostrom's model

It takes a village (TOC) > Creating coalitions > Governance of community coalitions

The US has no commonplace method by which localities can set priorities and implement improvements. Other countries do. They authorize the County Council, or the Primary Care Trust, or the public health office to assess the community situation, set priorities, engage in debates among advocates, defend the interests of the vulnerable, and act responsibly in the public interest. But not in the US! Local governments have very limited authority to control payments, services, or patterns of care. Local departments of health must generate various assessments and plans, but they do not control most of the flow of funds. Individual state governments have some of these authorities, but they are generally to large to engineer local reform. No other authority usually exists.

So, most localities in the US will need to develop voluntary coalitions to guide change in their own sites. Some can build on organizations already in place, for example, one built to share medical records (a health information exchange), or a chronic care coalition (usually formed around one illness or affected population, but able to grow), or a strong community-based social services organization. Convening what are often competing voluntary organizations is a fragile model on which to build governance. But it is what we have, so we may as well become good at it.

Building this sort of coalition requires a graceful mix of accommodating powerful entities that are willing, while keeping the welcome mat out for smaller players and initial skeptics. It helps for advocates to know their community very well. What "buttons" will move various entities to join in? It is almost never only monetary income. Usually reputation, opportunity for growth, and even personal commitments are weighty. But someone needs to know the players well, offer reasons to share in the coalition, make deals, and deliver on them. This work has to be anchored in the values of the community and respectful of the external structures such as payment and law.

CDC has developed a number of resources on coalition building and governance, mostly aimed at tobacco control, but translating to other targets is fairly straightforward.

In the Care Transitions work, some of the community groups built formal Steering Committees that made final decisions as to activities and priorities, with the Quality improvement Organization and the hospital(s) deliberately taking the role of participants rather than a controlling element. Others worked on informal consensus, with the QIO doing the convening and agenda-setting. One team deliberately brought in an outside facilitator so that the meetings ran more smoothly and the dominant hospital was perceived as being more of an equal participant. In some coalitions, people from the same provider always sit together; in others, people tend to sort themselves out by roles: for example, the nurse managers link up from multiple providers. A few more public coalitions, such as those writing a report to a state government, have operated with complete consensus, which is a risky practice in the usual coalition. Following the "rule" that no one gets a veto seems wiser. Often someone is skeptical and unwilling to invest but that party is often willing to let others try it out and let the evidence speak for itself.

It takes a village (TOC) > Creating coalitions > Building coalitions

Despite the challenges of building, governing, and sustaining a locally based coalition, remember that it offers the best opportunities for sustained improvement for your community!

The Centers for Disease Control have substantial resources on building and sustaining community coalitions, since they have been essential to public health initiatives such as tobacco control, stroke prevention, and domestic abuse. You will find many resources on the CDC's web site (www.cdc.gov). One useful starting point is the tobacco control program's handbook *Coalitions: State and Community Guide* (available at www.cdc.gov/tobacco/stateandcommunity/bp_user_guide/pdfs/user_guide.pdf).

A few guiding points from community-based health care improvement coalitions in the field:

- Keep the door open - latecomers may be eager to join later
- Allow no vetoes - parties that want to try something out and are able to do so are also free to do so.
- If there is one party with an overwhelming degree of influence, the meetings might go better with an outside moderator who can keep proceedings more equal.
- Nursing homes and mental health providers have been "beaten up" so much that their staff are often "beaten down" and resentful of being given second-rate status. Meeting in their setting or talking about what they did for shared patients can help establish respectful relationships.
- Process mapping is a tool that often serves to share a work process efficiently and thereby often illuminates inefficiencies and opportunities, especially regarding transfers where the multiple providers do not know one another's processes.
- Trading visits helps all parties to understand one another's settings.
- An intervention that does not work as planned is not a failure but an opportunity to learn something previously unknown about your system and its functioning.
- One of the Care Transitions sites had a participating facility that had been quite a bully in the past and the other participants were leery of trusting that facility. One interviewee said: "A bad experience has three times the valence of a good one." Clearly, it takes more experience to build trust than to destroy it.

In the Care Transitions work, some teams built substantial coalitions. One had the Lieutenant Governor and other officials announcing the initiative. Another had more than 300 community members come to a kick-off meeting and most signed up for working groups. The teams that engaged the most in community organizing also usually ended up with "Brand names" for the work, such as "Connected for Health" in Denver.

It takes a village (TOC) > Creating coalitions > Community-ness

The experience of the Care Transitions initiatives has been quite illuminating concerning the tendency of participants to work in the "community" interest, or even to "see" a community. In some cases, intensely competing hospital systems and their adherent clinicians recognize that they are part of a community in some vague way, but they are not really willing to work collaboratively, even on issues of disaster planning or public health (unless required by law or induced by payment). In other cases, a single dominant health care system identifies its interests as being entirely aligned with the interests of its community. While that is largely true, it is not always true that "what benefits General Motors, benefits the country." However, other clinical providers are often in too dependent a position to point out areas where the health care system should modify its behavior in order to work better with the community at large. In most communities, though, there are multiple hospitals with none being dominant, they cooperate in some arenas in the public interest and compete in others, and the "spirit" of community varies for other reasons. Ostrom's line of inquiry illuminates some considerations that might help guide this "middle muddle" of semi-formed communities.

What is it that allows one geographic "community" to come together and work on shared goals and leaves another having no identity or shared responsibility? Having other activities that define the community helps - e.g., a popular sports team, a spirited university, or an important business. Having a substantial distance to another community helps - cities with a lot of desert or farm land for many miles around have to develop some identity and self-reliance. Having a tradition of mutual assistance with few ethnic or socio-economic schisms probably helps, too.

In Canada, the health and social services of the provinces have recently been devolved to geographically defined authorities for coordination and budget (except for physician services). In Montreal, one of the defined areas is doing pretty well at building a commitment to the community and working together - better than the others. A social scientist studying the evolution of these entities (Ann Langley, personal communication) attributes this, at least in part, to the fact that a canal once ran across the island, and people living "on the other side" of the canal have a long tradition of pride in their place. This identification with the place, which maps to the local health and social services authority, gives them an advantage in working together. The Care Transitions initiative in Denver is anchored in two geographically close hospitals that chose to work together on these issues. The ZIP codes selected do not mirror a pre-existing community. However, the networks around the two hospitals turned out to be so effective that a community was effectively created by the two hospitals working together. They turned out 300 people for a kick-off event, kept most involved in working groups, and have advertised trainings by word-of-mouth travelling faster than formal pathways. The enterprise has joined into a "brand" ("Connected for Health") that has come to be widely recognized in the community.

See also, building community coalitions.

It takes a village (TOC) > Creating coalitions > Ostrom's Model

For many years, social sciences have accepted what is called "the tragedy of the commons," which reflects the commonplace observation that a group of people acting in their own self-interest will often end up harming the whole group by overusing limited resources. Thus, an unurganized group of farmers will overgraze a shared plot of land (the commons), and a group of independent lumberjacks will overharvest a forest. This observation usually leads to either wanting to have the resource under government control so that overuse leads to civil or criminal penalties, or under private control so that the owner can enforce limits on use.

Elinor Ostrom's Nobel Prize-winning work on voluntary institutions for collective action has shown that at least some long-sustained arrangements work to preserve resources without either government or private ownership. Her research finds that such institutions tend to have these characteristics:

- Total number of decision-makers is manageable
- Number of users willing to participate is enough to achieve the collective benefit (does not have to be all)
- The discount rate in use values the future - that is, the participants care about the resource into the future - they are tied to the place or the work.
- Similarities of interests among participants
- The presence of individuals with substantial leadership or other assets.

In health care, the money that the community puts into health care is the resource that can be overused in her model, and all the practitioners providing services are the users (or, in her terms, the appropriators). Can communities build on Ostrom's insights and build voluntary institutions that work in the interests of the community's health often enough that the system is reasonably equitable and efficient and thus is supported by the community? Or must we turn to government action to achieve these ends? [It seems unlikely that private ownership offers a generally useful model here, since few markets are so wholly dominated by a private entity and those that come to be so dominated might run into claims of anti-competitive anti-trust actions or simply profiteering without restraint in a community with few defenses.] In the US, Ostrom's model offers at least a slim chance for real success. If competing entities could cooperate on critical issues of coordination, community priority-setting, and ongoing system improvement, then we would need neither strong government action nor accepting the tragedy of the commons for health care. (see attachment for more of an introduction to Ostrom's work (hyperlink to attachment "Applying Ostrom")

What this means for local coalitions is that sustainable and effective coalitions are a very important contribution to the well-being of your community, even though they are difficult to build and sustain. Some communities are managing the feat - see, for example, the Grand Junction, CO, story in *Health Affairs* in September 2010.

It takes a village (TOC) > Act locally

- Why local reform?
- Defining the locality
- Geographic home care

It takes a village (TOC) > Act locally > Why local reform?

Especially with the recent passage of major health care reforms for the US, much attention has focused upon Federal and State policy on payment and quality. At the same time, more and more providers are actively implementing improvement activities within their own services, aiming to achieve higher quality more reliably. Both of these endeavors have generated substantial successes. However, some of the problems that Americans face regarding their health cannot be resolved without multi-provider coordination and improvement, and some will require changes outside of the health care delivery system. For both types of problems, some sort of local action is needed. Very sick people move across the care system, and their priorities, medications, treatments, family support, and other critical characteristics of the interaction with health care should not arbitrarily change or incur errors just because multiple providers are involved. Likewise, one can't imagine solving problems of inadequate housing for disabled persons or food deserts in poor neighborhoods by the action of medical care providers.

The Institute for Healthcare Improvement has generated a list of the considerations that argue for a major part of health care reform to be anchored in local action:

- All the components needed to construct a health system are within a region
- Common values are more likely to emerge
- Solutions to problems depend upon context, and context is known most accurately locally
- Platforms for dialogue exist or can be created
- Other health determinants are attributes of a region

Most other countries have a local health authority of some sort, which acts to adapt national and state funds and mandates to local priorities and possibilities. Sweden has county councils, Ontario has LIHNs (Local Integrated Health Networks), and England has Primary Care Trusts, for example. The US does not automatically have a local entity with substantial authority. Local public health offices have some responsibility, but usually little focus on chronic illness treatment and little control over money or planning for optimal services. Nevertheless, some communities have taken the opportunity to work together toward public aims, and they seem to be making substantial gains. Most will function as some sort of coalition, and building coalitions so that they can have some effectiveness and staying power requires skill and good fortune. Only in community-based coalitions can monitors of local health and health care make sense, and perhaps some kinds of innovation, such as geographically-based home services, can be tested.

It takes a village (TOC) > Act locally > Defining the locality

What is your locality? This may seem obvious, and if it is, then proceed with it! But if there are some overlapping possibilities, here are some things to consider.

First, geopolitical boundaries have some advantages. They are well-established and people know whether they live within them. They correlate with public health leadership, licensure and regulation, and therefore correlate with readily-available data about health and health care patterns. They are also natural for public information. So most local reform is likely to be anchored in city and county boundaries or their equivalent.

What are the disadvantages of relying on conventional city and county boundaries? Health care often crosses these boundaries, in complex ways. Thus, the three hospitals in one county might each serve at least half of their patients from other counties. But if you solve that problem by including a few other counties, the problem just keeps expanding because you add more hospitals with the same problem. Even more fundamentally, health care providers and insurers do not see themselves as having any particular accountability as defined by local geopolitical boundaries, and people living in a particular place may not be tied to any particular provider organization or insurer.

What else is possible? Dartmouth researchers working with Medicare claims (in fee-for-service health care) have defined geographic areas on the basis of how beneficiaries use hospitals. This effort resulted in the publication of the Dartmouth Healthcare Atlas and a related web site at www.dartmouthatlas.org. For example, there are 306 Hospital Referral Regions, or HRRs, in the US, and data from Medicare claims characterizes each of these. This work defines a rough "health care market area" in which the hospitals tend to provide services to this population. The allocation works out reasonably well, but some of the HRRS are huge.

Medicare has fielded a set of community-based initiatives that focus on Zip codes to define the locality, at least for purposes of measuring the effects of improvements on the population. Improvements usually benefit all users of the system, but monitoring can focus upon people living in the targeted ZIP codes. Obviously, such a plan depends upon there being a great deal of overlap. It may be possible to evaluate the overlap in your area. The 10th Scope of Work for each state's Medicare Quality Improvement Organization (QIO) includes making analyses of Medicare data available to communities in order to map and optimize the overlap between hospitals' service areas and geographic target populations.

In the initial work in Medicare, areas are doing better when the ZIP codes that are targeted define an area in which 70% or more of all transitions (from or to a health care facility) affecting Medicare beneficiaries living in that area involve hospitals and other facilities who are in the area's coalition working on improvement. But that condition is subject to a size constraint. Coalitions have to be able to bring key people together, face-to-face; and that means that you cannot realistically have a coalition for all of metropolitan New York. Many highly urbanized settings have such limited overlap that these two conditions cannot be met simultaneously, and prudent decisions about compromise will need to be made.

Which definition of your population should you use? Often, they are entirely or roughly congruent and the choice is easy. But when they do not converge, the coalition guiding the work will have to keep weighing the alternatives. It is probably most important to be thoughtful and stable in the definition of the population in which to measure progress. Inevitably, improvements will affect some people who are not in the population target, and some people who are in the targeted area will not benefit directly from the improved practices.

It takes a village (TOC) > Act locally > Geographic home care

Many people living with serious chronic illnesses or disabilities will need services at home in order to function well and stay as healthy as possible. At present, those services are provided by a broad array of agencies, each of which covers clients in a large area. Much of the direct cost of these agencies lies in coordinating services across such a broad area, and sometimes the aides and nurses spend half of their time just getting around. In addition, the local services in a large area are not well-developed or known to these participants, so they can't readily know whether a pharmacy might be willing to work out a delivery, or whether a church might be willing to check up on an elderly person at home.

In virtually every other country, home care services are organized geographically, so that any one aide or therapist has his or her clients located as contiguously as possible.

The fact that staff members have to move around a great deal leads also to mandatory minimum lengths of time, whether or not the client needs that much time all at once. Having multiple clients within walking distance would allow aides to be allocated more flexibly.

Coalitions have not yet tackled this opportunity, and doing so will require keeping competition in the marketplace. It seems to be an attractive option to work with, since better care and lower costs are possible. In some marketplaces, the competition among home care agencies is fierce enough that they do not invest in staff education or monitoring at the rate that would be prudent, so building in some staff development and quality improvement would be a useful way to employ the first savings that some geographic concentration would engender.

It takes a village (TOC) > Local priorities

It takes a village (TOC) > Local priorities > Setting priorities

Community groups tend to use mixes of two central considerations in setting priorities: what's most possible and what's most important. What's possible depends upon a prudent judgment as to

- the energy behind various complaints,
- the established pathways that are known to work in remedying the problem,
- the existing tendency to have enough cooperation and leadership on the issue, and
- the need for and availability of resources.

But how can a community set priorities? No one is comfortable with just listening to the loudest voices, in part because we know that the most vulnerable people often have little access to the community soapbox. Here are some possibilities for more data-driven community self-assessment as to priority challenges for health and health care:

1. In virtually every sizable community in the US, the public health office will have generated a series of written strategic plans (e.g., on infant health, on chronic disease, and on cancer). Those vary, of course, in how data-based they are and how perceptively they were put together. Perhaps more important, many are far out of date. But the Centers for Disease Control provides most of the funding and a good deal of technical support, so they tend to have a certain legitimacy and reliability. It is worthwhile to unearth those and perhaps also to talk with the staff who worked on them.
2. A number of indicators of health by county are available on-line at countyhealthrankings.org. These indicators focus upon community drivers of health and not mainly on health care itself.
3. Many insights about your health care system arise from exploring existing analyses of Medicare claims at dartmouthatlas.org. Their site allows a variety of comparisons, but the user must remember that its data is entirely from fee-fo-service (traditional) Medicare, so these data provide a useful reflection of overall performance and they directly measure performance for older persons. The boundaries that the analyses used to define geographic populations are well-described on their site, but the user should become familiar with the different ways the Dartmouth group creates boundaries from data analysis, since these vary and they will not be as familiar as are county and city boundaries.
4. Your state and local public health office will have reports and staff who know a great deal about illness burden in your locality, and often they have the capability to run additional data analyses. Likewise, you may have a nearby university whose faculty members have been studying some aspects of your community's health.

Of course, data does not speak for itself. Sometimes the politics and relationships dictate the opportunities, especially at first. But over time, one hopes that a balanced approach evolves. See "Bridges to Health" model and Overall Goals.

It takes a village (TOC) > Local priorities > "Bridges to Health" model

Most public discussion of health and health care uses two ways to structure the categories: either by disease or by provider of services. Thus, we have disease-based advocacy organizations (e.g., for breast cancer or Alzheimer's dementia), chapters by disease in medical and nursing textbooks, and report cards and guidelines on the quality of services for affected people. And we also have funding and quality measures directed to various providers: hospitals, physician offices, day care centers (for young and old), senior centers, and so on. These two methods have their uses, but they do not optimally reflect the experience of care from the patients' perspectives.

Many countries and major health systems in the US are coming to use categories that are framed in terms of the populations served. Using this approach, they examine how well the whole community system is functioning in terms of maternal-infant well-being, or in terms of supporting the frail elderly. Then, all the diseases that are common in that population and all the service providers for that population are understood as a working system, where the task of the community is to optimize ongoing outcomes, assure equity, and assure efficiency. This approach is especially useful in focusing the task of prioritizing opportunities for improvement, since it puts the patient group at the center, accepts their priorities, and recognizes that most improvement needs involve both multiple diagnoses and multiple providers of services. Thus, for example, one does not focus on the hospital's role in discharging heart failure patients; instead, one frames the issue as how the sender and receiver interact in assuring safe discharges of persons with serious chronic conditions that require ongoing services. One useful categorization of the population is the "Bridges to Health" model which split the population into eight segments. (For an overview of the "Bridges to Health" model see: www.milbank.org/quarterly/8502feat.html) .

1. Healthy
2. Maternal-infant health
3. Acutely ill, likely to return to health
4. Chronic conditions with normal daily function
5. Serious relatively stable disability
6. Short decline to death
7. Repeated exacerbations, organ system failure
8. Multi-factor frailty, with or without dementia

The "Bridges to Health" model's categories are not rigid - you can redefine them to fit how your team thinks about its population. Some have split out serious mental illness in category 5, for example. Many teams have renamed the categories to reflect local usage. The main point is just to focus upon a relatively small number of sub-groups who make up your population and then assess performance and opportunities on the basis of what each population most needs.

This approach has the virtue of recognizing the rather different priorities of different phases of the life. It is reasonable to put a very high premium on healthy children, even with some added burdens on their mothers, since that is the common priority of the mothers themselves. And it is reasonable to prioritize support at home and comfort for the frail elderly, again because that tends to reflect the priorities of the population. Of course, practitioners directly providing services need to have flexibility that allows them to match care plans with the particular patient's situation and preferences; but it makes a great deal of difference to have the population-optimal services readily available rather than assuming that everyone equally wants to try rescue chemotherapy but disdains good nursing home care!

Some teams have developed a prototypical patient for their target population and measured improvement in terms of what that person needs - for example, the Esther Project in Sweden. (See: www.ihi.org/IHI/Topics/Flow/PatientFlow/ImprovementStories/ImprovingPatientFlowTheEstherProjectinSweden.htm)

"Esther" is not a real patient, but her persona as a gray-haired, ailing, but competent elderly Swedish woman with a chronic condition and occasional acute needs has inspired impressive improvements in how patients flow through a complex network of providers and care settings in Höglandet, Sweden. Esther was invented by a team of physicians, nurses, and other providers who joined together to improve patient flow and coordination of care for elderly patients within a six-municipality region in Sweden. The productive work that has been done on Esther's behalf recently led the Jönköping County Council, responsible for the health care of 330,000 residents living around Höglandet, to become one of two international teams participating in the Pursuing Perfection initiative. This program, launched by The Robert Wood Johnson Foundation, is designed to help physician organizations and hospitals dramatically improve patient outcomes by pursuing perfection in all their major care processes. The Institute for Healthcare Improvement (IHI) serves as the National Program Office for this initiative.

It takes a village (TOC) > Local priorities > Motivations to address costs

For many years, the US health care system has been mostly blind to the escalation of costs, and your coalition may choose not to work on costs, at least at this time. However, many coalitions will have concern for rising costs as part of their community mandate, so it is worthwhile to consider how those considerations might help to forge a coalition and to generate the will to undertake reforms.

The fact of obvious waste in the system is enough to offend some prudent people. In many systems, the results of tests done in one place are not available in the next place, and the patient's care needs those results. Often, the tests are repeated because it is so difficult to get the previous results. That system dysfunction is generating waste. Often a patient bounces back from the nursing home to the hospital because critical pieces of information about the plan or goals of care did not come with the patient: that is also a waste of resources (and sometimes worse, in that rehospitalization often poses risks for the patient). Examples are easy to find, and they generate frustration and weariness among health care providers and misuse of community resources for all (since most of health care relies upon shared funds through insurance or through government payments). Some communities have even more pointed reasons to take up the costs of health care. In some communities, businesses work in global marketplaces and the high cost of health care in the US puts them at a disadvantage. This is a concern for all in the community, since jobs and community well-being turn on having profitable businesses. In other communities, demographics are shifting to put pressures on the supply of costly health care resources. For example, the overall population may be growing, or there may be disproportionate immigration of elderly or poor persons with higher health care needs. At one time, public funds would be available to build hospitals and clinics, but financing these expansions has become much more of a community burden. Building a new hospital bed is often said to cost more than $1million, and financing is not readily available and payback will take many years. Thus, communities sometimes have strong reasons to see whether they could use their existing resources more efficiently, rather than taking on these additional costs.

More and more communities are just forecasting that costs are going to have to come under control as a matter of restoring a well-functioning economy and they want their community to be ahead of the curve. The Care Transitions initiative by Medicare's Quality Improvement Organizations uncovered a widespread conviction by hospital leadership that rehospitalizations were going to become financial liabilities very soon. Indeed, some sites thought that they already were not paid at the going rate. The Accountable Care Act of 2010 created financial penalties that start at 1% in 2013 and escalate to 3% of Medicare payments, for hospitals with persistently high rates of rehospitalization within 30 days of discharge. Most hospital leaders talked about non-payment as if it were already true until asked, when they responded that it was not yet true but would be soon. Only a few were still skeptical, saying that they'd deal with it when it was more likely to happen soon. Those skeptics are probably now convinced.

Having a strong, locally supported reason to want to forge an efficient health care system is a real advantage for that community, since it helps to keep the components of improvement in balance: one cannot propose to improve things simply by building (and using) more capacity - one has to address the dysfunctions that are causing inefficiencies in the community's service delivery system now. However, dealing with costs in health care is politically difficult. Every dollar now spent in inefficient care is someone's income, and most expenditures have at least some putative component of usefulness (even if, on average, it does not work out that way).

It takes a village (TOC) > Local priorities > Rationing

For many years, public allegations of "rationing" have been enough to stop most efforts to constrain costs. In the last round of "health reform" that resulted in the Patient Protection and Affordable Care Act of 2010, a completely erroneous allegation that the bill would somehow generate "death panels" derailed a set of payments to encourage discussion of prognosis and care planning, which had no rationing role at all. Of course, it is true that US health care has always had limits - some set by capacity (e.g., only so many transplantable organs available), some by distance or poverty (e.g., patients unable or unwilling to take on the burdens of co-pays or travel), and some by underpayment (e.g., limited support for disabled persons at home). But most of those limits were either temporary or indistinct, so that it was not easy to spot who was denied services and the limitations mostly did not garner public attention.

We have thus maintained the sense that the ideal is for every person to have access to every service that might be of help in achieving health and longer life. Community coalitions are not likely to take a different stance. Mostly, community coalitions are going to be working within the scope set by Federal and State action in managing their local systems. The good news is that the system dysfunctions offer plenty of opportunities for efficiencies without having to make proven interventions unavailable to patients who could benefit (or, in other words, to ration services). Nevertheless, many efforts to improve efficiency will be cast as efforts to ration services and thereby become very difficult to sustain. A patient who really wanted to get that extra test will claim that it might have been important in his or her care, or a patient who can't accept that there is no treatment left that has been shown to work still wants to try a costly intervention.

There is no easy way to prevent running up against these issues if your coalition aims to work on costs at all. However, a couple of approaches might help.

First, developing a strong allegiance to the evidence helps limit the claims of desperate people or creative providers. If someone wants to try something that "might work" but for which there is insufficient evidence, that can be categorized as experimental and available only in funded scientific research (not on an individual basis). Sometimes, the evidence is regularly and systematically reviewed, so allegiance to the generally thoughtful and comprehensive reviews of organizations like the US Preventive Services Task Force or the Food and Drug Administration is a first step. That means, for example, that the community coalition would back the recommendations of the USPSTF on not routinely screening women under age 50 with mammograms. Second, encouraging use of lower cost treatments before authorizing higher cost treatments is generally prudent. Monthly costs of pills for diabetes can vary one-hundred-fold. If a patient does well on an inexpensive remedy, they should not be given the expensive variety. Sometimes, of course, patient preferences weigh in, but more often it is provider preference that is leading to starting with the expensive approach. So, education and incentives might set out to encourage prudent stewardship of what are always mostly community resources that support health care.

Third, reformers need to keep in mind that they often only have to affect "most" of the practice. It is often better to allow a few outliers with strong objections to lag behind and waste some than it is to stop all progress and fight it out. For example, if now most nursing home residents get resuscitation tried when they go to the emergency room, then getting most to have advance care plans will make substantial gains in matching services to preferences and in reducing costs. But if a few doctors really object or a few families find this troubling, it might be better to give them some time to come around than to insist upon a standard practice of planning ahead that some might (wrongly) label as rationing and thereby delay or thwart other initiatives. See also measuring costs and motivations to address costs.

It takes a village (TOC) > Measurement

It takes a village (TOC) > Measurement > Using measurement

Most improvement activities make an error in how they invest in measurement - they either spend so much time and effort making measurement precise and reliable that they elegantly measure the lack of progress (the academic's error), or they measure virtually nothing and don't know what they achieved (the anti-academic's error). The trick is to measure enough to be sure that improvements are working and not causing trouble, without tying up your resources (including enthusiasm) so much that nothing can get done! Sometimes the rule of thumb is to assume you have 10 units of effort to put into improvement - aim for 3 or 4 into measurement.

Measures of system performance often pass through a series of maturing perspectives:

1. Intrigue - "Can you show me more about what we are doing?"
2. Rejection - "That just can't be right."
3. Blaming - "It's right, but the problems are someone else's responsibility"
4. Powerlessness - "It's right, and it's mine, but there's nothing I can do about it."
5. Exploration - "It's right, and it's mine, and maybe someone has some ideas?"
6. Commitment - "It's right, and it's mine, and we are going to fix it."

Simultaneously, there is often a growth in the ability of the initiative to find and use data. So you may start out only with publicly available metrics, then some of the providers can supplement from their own data, and then you find that someone - perhaps the Quality Improvement Organization, the Department of Public Health, a local insurer, or a university faculty member - can do some customized data analyses for you. Perhaps over time, the coalition starts to develop its own in-house or contracted capability to do analyses. And there is usually a growth in the willingness to have and to share data. Most coalitions start with substantial suspicion about the harms that might arise if others knew more about their practices and finances. Over time, working coalitions both generate agreements about limits on disclosure and gain the trust that data generally helps rather than harms them.

Measurement usually requires measuring outcomes that matter, processes closely tied to those outcomes, and potential harms arising from the changes. Most measurement relies upon samples if the numbers affected are substantial, and the sampling strategy needs to be simple and stable (e.g., the first five patients each afternoon). Unlike most medical research, what matters most is the trends, and you can usually accept substantial error in the "point estimate" of the actual rate, so long as the error affects every measurement equally.

Mostly, you will want to plot measures over time, using the X-axis as time and the Y-axis as the item you are measuring (usually a rate, like the number of people who had a fully reconciled medication list within 24 hours, divided by the number of hospital discharges). Then you annotate the timing of the various improvement strategies and other events that affect the rate, and the team can usually interpret the merits of their approaches. There are more rigorous elements of the method, and you can learn them at the IHI Open School. (See:http://www.ihi.org/lms/onlinelearning.aspx)

You may have a natural comparison group, in that there may be part of your system that is not yet using the improved process but can readily be measured. Obviously, showing that the comparison group is puttering along with poor performance while the improvement site has a good trend can be powerfully motivating. On the other hand, you almost never would have reason to do a randomized study of your intervention. It is very hard to improve system function for one patient and not for the next patient, so improvement activities in one setting tend to "contaminate the control group," and, indeed, you want them to! Change is so hard to achieve that you usually do not want to limit its application. If you are going to improve the discharge process from hospitals, you usually cannot do it only for the heart failure patients, or only for five patients each week. Improved processes end up applying to everyone going through the system.

Furthermore, trying to engineer strong research designs puts your project under review as research on human subjects, which is quite appropriate, but that entails substantial rigidity and delay that is usually unhelpful to quality improvement. So, be thoughtful before pursuing research goals in a QI project! It seems that data are used in the following ways in many initiatives to improve health care:

- To open doors - to get providers and funders interested
- To galvanize a movement - an easy-to-remember fact serves to sum up the need for change
- To block trials of some changes because they did not work in another setting
- To monitor change and set goals

Most likely, having stronger data and ways to monitor it would help move improvement along better. See also, Common Data Sources, Measures of Population Health, Measures of Patient Experience, and Measures of Cost.

It takes a village (TOC) > Measurement > Common data sources

This list gives some data sources concerning health and health care that are commonly available to communities in the US:

1. Vital records - available in every jurisdiction - usually familiar to the Department of Health epidemiologists - can be mined for combinations of age, race, diagnoses, being in hospital/ER/nursing home at the time of death (often requires cross-matching addresses for nursing homes) - one does have to be careful about attribution rules about primary cause of death (which probably routinely attribute death from prostate cancer in elderly men who really die of frailty, for example). But at least vital records are collected in nearly the same way over long periods of time and have few restrictions on use (because the person is dead and has no privacy rights per se). One interesting additional possibility would be a death certificate follow-back on a sample of non-accidental deaths. This could be done relatively inexpensively and would yield data and stories likely to be salient in the locality.
2. BRFSS - Behavioral Risk Factor Surveillance Survey - available in every jurisdiction - core set of questions is asked throughout the nation - local questions can be added relatively inexpensively - local public health epidemiologists will be familiar with it - sampling biases are adjusted by CDC formulae so that annual reports reflect the population (raw data are much harder to work with - many biases). Now asked in ish and English - and on cell phones - but does not get people who are institutionalized, people who only speak other languages, persons without phones, persons who won't talk on the phone, and others. Furthermore, the cell phone responders can only answer the core questions. The target of the survey is mostly risky behaviors and conditions appropriate for preventive health interventions (smoking, etc) but localities can add others around any topic of concern. BRFSS includes a question on self-reported health.)
3. MDS and OASIS - Every person who is resident in a nursing home has a "minimum data set" (MDS) reported to their state and then to CMS at admission, discharge, every 90 days, and with major changes in health status. Every person whose home care is paid by Medicare and most of Medicaid has a similar data set (OASIS) collected and sent to the state and to CMS. (And many home health agencies just collect it on everyone, but analyze the data that includes other payers only internally.) Depending upon the rate of use of nursing homes and home care as after-hospital care settings, your area may have most of the people who are very sick going through nursing homes and/or home care. Since the data is collected on everyone in a standard way, one could generate a number of insights as to the experience of people who are living with major illnesses and disabilities. For example, one could estimate the rate of serious pressure ulcers, the use of restraints, the prevalence of advance care plans, and the status of family caregivers. These databases have been used mostly for regulatory and financial purposes, and not for monitoring quality, so analytic approaches would need to be developed.

4. Medicare Claims - Medicare fee-for-service claims are a rich and well-used source of insights. Getting the data requires privacy protections, a good deal of skill in working with the data, and tolerating a substantial delay. CMS can get its own data within about 4-8 months now, but researchers mostly have one-per-year downloads about a year after the end of the year (so some data is two years old). (check) One potential source of access to Medicare claims might be through the QIO that serves your area. At present, the QIO would face substantial delays in getting CMS permission to help you with the data, but that may change with the new emphasis on accelerating innovation. Some QIOs have substantial expertise in analyzing Medicare claims, and all have access to programs developed by others. What can you learn from Medicare claims? Hospice program use, location at the time of death, utilization of health care over a time period, utilization of ventilators/feeding tubes/high cost treatments/multiple providers, rate of pressure ulcers, rate of CPR efforts (and outcomes), survival after specific interventions, and more. Medicare claims have mostly missed managed care and hospice (other than the fact of enrollment for a period of time), but new requirements are filling in some of the data in those settings. The Colorado Foundation for Medical Care (cfmc.org), under contract with Medicare, has developed a couple of very useful SAS programs that line up all of one patient's claims chronologically and translate them to a readable format. Examining a sample of such claim streams can illuminate patterns of care and possible points of improvement. They also have a program that examines the transitions between settings for a population defined by Zip code and identifies penetration of each Medicare provider in the ZIP code-defined market and common patterns of transfer (with a facility as sender or receiver) .
5. Medicaid claims - theoretically, one can do most of what can be done with Medicare with the Medicaid data, but many states do not have the data cleaned up and ready and do not have analysts skilled at looking at Medicaid data. Also, many states have most of their beneficiaries in managed care and get very little data on these patients. Furthermore, eligibility for Medicaid often is intermittent. Nevertheless, dual eligible (Medicare and Medicaid) patients often have substantial Medicaid records, and many states have learned a great deal just from examining outlier payments or high-cost codes. Merging Medicare and Medicaid databases can yield a powerful database for local reform. About 80% of people who die are in Medicare, and probably an overlapping half are in Medicaid.
6. Chronic Data Warehouse - CMS compiles claims, MDS, OASIS, and a few other databases into a consolidated record for research. Local researchers under contract to a community coalition could generate proposals and get permission to use the CDW data. The cost per year per data run varies.
7. RHIOs (Regional Health Information Organizations)- some areas have cooperative health information interchanges to support better clinical care and surveillance for bioterrorism or epidemics. That activity generates a useful database that some are learning to mine for measures of quality and population health. Sometimes, the exchanges were set up without attention to this possibility, and then you have to get appropriate usage agreements. If the RHIO has most people and services in the community, analyses can illuminate what is happening at a clinical level in that population. This can include all ages and conditions (except for military, veterans, incarcerated persons, and Native Americans who use separate government health care that usually does not participate in the RHIO) In areas without a functioning RHIO, one might still find that some critical elements of the care

system are concentrated in one or two providers and that tapping into their data may show important indicators. For example, outpatient laboratory data may sit in one or two companies, or virtually all patients with a particular illness or disability may use one provider.

8. Local utilization reporting - many jurisdictions monitor at least ER and hospital use and sometimes certain laboratory tests in order to detect public health threats. These databases might be mined for additional useful information.
9. HCAHPS (Hospital Consumer Assessment of Healthcare Providers and Systems) and other CAHPS (Consumer Assessment of Healthcare Providers and Systems) mandated by CMS - these are surveys of patients, sometimes of all adults as in the Hospital CAHPS and sometimes only of Medicare patients who use particular service types. These data are used in the on-line reports of hospital quality that are available for most hospitals. Hospital quality data is available at the Hospital Compare web site (www.hospitalcompare.hhs.gov). Similar data are available online for nursing homes (www.medicare.gov/NHCompare) and for home health agencies (ww.medicare.gov/HHCompare) and will soon be available for physicians and other providers.
10. Existing quality measures already reported - e.g., HEDIS for managed care plans, and CMS quality measures for nursing homes, home care, and hospitals. In most cases, the raw data is not readily available, and the quality reports have various problems including delay, but they are available at no added cost.
11. Tumor Registries - every cancer and brain tumor diagnosed in the country is recorded in the local, state, and national tumor registries, along with demographic information, precise diagnostic information, and initial treatment. Prevention and screening services are not included, only diagnosed cancers and brain tumors. However, if your coalition is concerned about cancer in the community, the local tumor registry is the place to start finding the data. States organize their local registries in different ways, sometimes having only hospital-based and state registries and other times having county or region-based databases as well. You can start with your hospital's registrar who will know how the system works in your locale. Working with these data usually require either persuading the government epidemiologists to do analyses for you or working with someone who can handle privacy issues (such as an academic researcher), since these data are identifiable and affect living persons.

It takes a village (TOC) > Measurement > General measures of population health

Many measures provide insight into the health of a population. The US was stunned when the military draft during World War I and World War II showed that nearly half of the conscripts were not healthy enough to serve. Since then, various programs have helped secure better nutrition, dental care, medical care, immunization, and other services to give children a reasonable chance to grow up healthy (though recently obesity is eroding these gains). But how would one know if actions taken really yielded better health?

One simple measure is longevity, and it is certainly a triumph that life s have nearly doubled since the start of the last century. Average life expectancy at birth is a reasonably sensitive metric to monitor community health. Localities usually have vital records data by county or city that already give this measure, and they usually could adapt it to some different boundaries if asked.

A somewhat more sensitive measure of longevity is to look at life years lost before an age that the community feels is a reasonable target for all, such as age 75 years. Using a metric like this does not in any way mean that years beyond that age are less valuable, just that deaths earlier than that are likely to call for community action. So, if there is a population who often die in their fifties, a measure like this will highlight their problems whereas an overall measure of life expectancy might average them out and make them less visible.

Another element that matters Is whether the years lived were healthy ones. Many different measures provide information on that, but one simple possibility is to use self-reported health status. A national survey called the Behavioral Risk Factor Surveillance Survey, or BRFSS, provides estimates for every county and state of the rate at which people rate their health as excellent, good, fair, or poor. Having fair or poor health correlates with being sick, dying sooner, being less productive, and other adverse effects. Using vital records and BRFSS self-rated health status, one can generate a measure that combines the two ideas into a useful indicator of overall health: either life expectancy in good/excellent health or years of life before age 75 in good/excellent health. One tool for this purpose can be found at the County Health Rankings web site, that allows you to look up data for your state and county (www.countyhealthrankings.org). The epidemiologist in your public health office can usually generate this metric every year, about six months after the close of the year.

In addition, most communities will want to monitor some more specific measures of population health - ones aligned with their specific initiatives.

It takes a village (TOC) > Measurement > Specific measures of population health

In addition to general measures of population health, myriad possibilities exist for measuring population health more specifically. One commonly used measure is infant mortality, which reflects not only perinatal care from health care providers but also the health of mothers and the support of infant health in the period just after birth. The same kind of monitoring is possible around specific illnesses or subpopulations. For example, one can examine the age and cause of death, looking especially for causes of death that affect younger persons (e.g., violence) or that affect many people (e.g., heart disease) or that should be mostly preventable (e.g., AIDS). In a sense, measures of population health show the overall effect of all the conditions - medical treatment, environment, genetics, workplace safety, etc.

It takes a village (TOC) > Measurement > Measures of patient experience

One summary measure of the experience of patients (and families) is to ask questions about how they judge the care they are getting. Especially in a situation in which the community shares extensively in the costs, the general approval of the patients and families is critical to sustain. However, it does not usually work well simply to ask these "customers" about whether they are "satisfied" because most people claim to be satisfied with very deficient services, and some are never satisfied, so the number of respondents whose responses actually reflect the quality of care is often too small to be convincing as to whether things are getting better or worse. It turns out that people are much more capable of reporting distinctions if they are asked to report on events as successes or problems. And people are much more able to report the degree to which they trust the providers. Thus, one often does not learn much from asking whether people were satisfied with the treatment at "General Hospital" or "for your heart attack." But one can learn a great deal quickly by asking a sample of patients whether there was ever a time while at "General Hospital" when you had to wait for much too long for a medication to be given, or whether you and your family felt confident that you would know who to call for symptoms after discharge. The measures you choose to use will, at least at first, probably reflect the aims you have and the changes you want to implement. As you work along, you will find that some measures are worth keeping even when you've mostly solved that problem, just to keep an eye on backsliding; or that some are worth monitoring over the long term to keep guiding slow change. You may also find that you want some "generic" measures of how well the community respects and relies on its care system - in part to watch for any declines.

You may well also want to consider the IOM list of characteristics that make for quality in health care discussed in the section on goals. If you take the measures your coalition is using and check them against this grid, you might see that you are concentrating in one or two areas. Then you might pause to consider the opportunities in other areas.

	SubPopulations > All (See: "Bridges to Health" model)								
Characteristic of Quality	**Healthy people**	**Mothers and young children**	**Injuries and short-term illness**	**Chronic illnesses with normal function**	**Long term disability**	**Short term decline**	**Organ system failure**	**Multi Factorial Frailty**	**All residents in the area**
Safe									
Effective									
Timely									

Efficient									
Equitable									
Patient-Centered									

See also Using Measurement

It takes a village (TOC) > Measurement > Measures of cost

Increasingly, businesses, employees, senior citizens, and ordinary Americans are concerned that health care costs come into balance with other things that people need and want, rather than continuing to use more and more of the community's resources. But of course, we also want to have all of the benefits of modern medicine. At least at this time, there is usually enough inefficiency in the system that major gains can be had in holding down costs without having to consider limitations on demonstrably effective treatment. Localities can therefore monitor the costs of health care and aim to limit cost increases. For example, some projects aim to hold increases to no more than 3% per capita. Others have chosen to try to keep per capita costs the same, or to have no increase in commercial insurance costs. It is complicated to calculate the total costs of care, since many costs are in long term care, private expenditures, or uncompensated care. But usually there is a way to provide an indicator that is sufficient to monitor trends, even if it is not comprehensive. One can add up hospital, nursing home, physician office, and medication costs from billing data, if there is a reasonably complete set of claims. One can monitor health care costs of a major employer or set of employers. One can even just monitor Medicare and Medicaid costs, which usually should be available in a reasonable time frame.

See also: Using measurement

It takes a village (TOC) > Fixing care transitions

- Fixing hospital discharge processes
- The Medicare Care Transitions experience
- Targeting rehospitalization

It takes a village (TOC) > Fixing care transitions > Fixing hospital discharge processes

Moving a sick person from one setting of care to another is fraught with challenges and errors. Some have estimated that the average hospital discharge includes at least one serious error that could cause harm. The risks of moving around in the care system have increased in recent years because of the increasing segmentation of service providers. No longer does the usual patient have the same physician in all settings - now the hospitalist service manages the hospitalization, the nursing home team takes over in that setting, and the outpatient physician gets the patient back with no more than a one-page summary. The usual patient has become much more complicated also. Fifty years ago, few people lived long with advanced heart disease, for example. Now, many people spend many years depending upon a complicated balance of multiple medications, structured diets, and other treatments, all of which regularly undergoes upheaval with a change in illness and setting of care.

A current project of the Centers for Medicare and Medicaid Services, the Care Transitions Theme for the Quality Improvement Organizations, is among the initiatives that have taken on improving transitions in the care system. A summary of that project, along with a table of the research-proven strategies for improvement, is available online through the Colorado Foundation for Medical Care (www.cfmc.org/caretransitions/files/Care_Transition_Article_Remington_Report_Jan_2010.pdf). The 14 communities involved in Care Transitions are learning a great deal about what works, how to adapt the research findings, and how to generate workable coalitions. In addition, the project has had talks and powerpoint presentations from virtually everyone working on improving care transitions in the country, and they are all available at http://www.cfmc.org/caretransitions/learning_sessions.htm.

Most of the leading research and implementation endeavors have user-friendly websites:

- The Coleman model for teaching patients self-advocacy: www.caretransitions.org
- The Naylor model for providing nursing support: www.transitionalcare.info
- Project RED (Re-Engineered Discharge) using computer support: www.bu.edu/fammed/projectred/
- Project BOOST, a hospitalist initiative: www.innovations.ahrq.gov
- STate Action on Avoidable Rehospitalizations (STAAR), working at a state level: www.ihi.org/IHI/Programs/StrategicInitiatives/STateActiononAvoidableRehospitalizationsSTAAR.htm
- Hospital to Home (H2H), focused on cardiovascular conditions: www.h2hquality.org

Some of the interventions that proved effective in improving transitions were:

- Simply having the "senders" and "receivers" get to know one another. From one site visit: "Can you imagine that just one year ago, I would send a patient off to the SNF with whatever I could throw together and count on luck for it to work out. Now that I know the people there, I could never do that. We make sure they have what they will need. Every single discharge gets the information faxed and then a follow-up call to answer any questions before the patient leaves here."
- SBAR (structured Situation, Background, Assessment, and Recommendation) communication from nursing homes to on-call physicians, including advance care plans such as POLST, thereby teaching even unfamiliar physicians more about what the nursing home could do See the INTERACT II website as an example http://interact.geriu.org.
- Teachback - a technique that has the learner (the patient or family caregiver) tell the teacher (the nurse or doctor, for example) what they have learned from the interchange. This gives the teacher the immediate opportunity to reinforce or modify what was learned and greatly adds to the retention and usefulness of learning, e.g., about medications or self-monitoring.
- Exchange visits to upstream and downstream provider sites, either for a meeting and tour or for a whole day. The longer visits clearly generated more mutual respect for the tasks facing one's peers in another setting. From a site visit: "Hospital staff members were surprised to find how resource-limited the SNFs were, while the SNF visitors were impressed with the caseload and time pressure on the hospital staff." From another hospital-based visitor to SNF: "It is hard to imagine how they do it with no nurse educators, no computers, no specialists - often no doctors around!"
- Structured information transfer
- Electronic information transfer - However, the "receiver" in a transfer has to be able to use electronic information. One hospital put together a good package of electronic information to send to their SNFs without realizing that the clinical nursing team had no access to computers.
- No transfer without notification, with oral or faxed "ok"
- Study of reasons for readmission
- Meetings of upstream and downstream providers
- Process maps across settings, jointly produced and critiqued
- Medication reconciliation, though this turns out to have many complexities. See Too many med lists as an example.
- Trigger tool for palliative care
- Targeting tool to identify higher risk patients and provide care management
- Volunteers to provide coaching - worked well in some settings and not at all in others - seemed to depend upon finding older, mature volunteers who enjoyed having acceptance by hospital staff, rather than college students on a short-term assignment. Can require training in standard clinical practices like infection control and privacy.
- Data from direct measurement as to how well the discharge process is working
- Recognition that the community system will function much less well if certain elements, mostly those serving the poor, are not sustained; and therefore, sending only the patients with the most complicated and underfinanced needs to those providers may put them out of business and thereby worsen both the community health and the demands on other providers.

- Hospitals sometimes helped SNFs to use electronic data, providing training and sometimes even computers. In at least one case, the hospital expects to repeat the training every six months, in anticipation of the usual nursing home staff turnover.
- Getting appointments in the 4-7 day time frame that is usually optimal after a hospital discharge requires cooperation from the physician offices. In one system, the Care Transitions QIO worked with the office managers to be sure they understood why this was important and how to achieve it (using principles of flow to achieve same-or-next-day service in offices generally), and got post-hospital appointments routinely available.
- Getting more routine rounds by nurse practitioners or physicians at skilled nursing facilities, so that discharged patients or newly more ill residents can count on being seen promptly.
- Expanding the scope of what SNFs are able and willing to do - e.g., to give furosemide IV and check on outcome in a couple of hours, before sending a fluid-overloaded person to the hospital.
- Palliative care - e.g., more advance care planning in all sites, more symptom management, more palliative care teams, more referrals to hospice.
- Getting multi-facility accord on "do not resuscitate" orders so that they are not routinely abrogated with each transfer (and require being re-discussed before being reinstated). State adoption of POLST is helping this situation, in that the POLST is usually honored in all settings. In the absence of such a state-level accord, local agreements between emergency medical transport, hospitals, and nursing homes (at least) are plausible.
- Encourage arrangements in which a physician who provides care for multiple very sick persons living in the community can work mostly with a home health agency team, so that all parties get to know one another and can communicate efficiently and frequently. The referral patterns in some communities are ensuring that such a physician will have virtually as many home health care teams as he or she has patients needing those services, which makes it very hard to coordinate services and provide support.
- Be thoughtful about improving referral patterns that send only difficult and expensive patients to the one or two "non-profit" home care or nursing home providers in the community. Without some other means of support, those providers are going to have substantial disadvantages and may not be able to continue.
- Make sure that the nursing home or home care nurse who calls the emergency room to give a report on a patient coming to the ER is treated with priority and respect. Multiple teams found that such a call-in was routinely handled by a non-clinical clerk and the information was not promptly put into the ER chart. Moving such a call to the clinical team and giving it in SBAR format greatly improved communication.
- Be sure that email addresses, fax numbers, and text message destinations are kept current. One hospital found, when doing a marketing mailing, that only 19% of the fax numbers for their community physicians were correct. No wonder the physicians claimed not to have received the discharge summaries! Usually about half of addresses become incorrect within two years, so a method of checking and updating will need to be built into any electronic communication system.
- Patients and families refusing offered services can complicate efforts to reduce the trauma of transition. Methods to reduce refusals and to provide back-ups that are acceptable are still needed.

- Transitions are often considered only in well-travelled patterns: home or nursing home to hospital, and hospital to nursing home, for example. Some teams found substantial opportunity in deliberately considering other possibilities: ER to hospice, or home health agency to nursing facility for respite care. One team realized that 75% of home care enrollments in a nearby community came straight from home, often thereby avoiding the ER and hospitalization.
- Participants often really enjoy this work - they like the networking, the improvement in patient care, and the opportunity to get "beyond whining" about the situation. In many cases, this was the enduring fuel for ongoing work.
- One hospital has arranged to put a list of key discharge information on a secure website. The discharging physician sends a text to the outpatient physician to say that the information concerning a particular patient is there, and then gets a text message back to confirm. Until the return message comes back, the responsibility stays with the discharging physician, so having no confirmation leads to a phone call.
- Most of the teams generated some sort of patient-controlled record, usually in hard copy (though the one site with many patients having personal health records on-line used that resource also). These were usually about the size of 4 pieces of paper folded in half, and some were produced informally and others printed in style. These were given to complicated patients and kept up by all providers that they were using. Patients picked up on this well, and some sites had very high rates of use. Indeed, one problem was that patients were sometimes getting multiple such handbooks for their personal use (e.g, one from the hospital, one from their primary provider, one from their nursing home, and one from their cardiologist). Getting the patient health records back to one version was requiring another step of standardization and the ability to rebrand an item that had become a point of pride (and marketing) for the provider.
- Some patients end up with overlapping, inefficient services - coaching from a Care Transitions initiative, CHF follow up by phone from a CV nurse, and also home health agency in-home follow up teaching. At the least the messages need to be standardized, and in addition, the work probably needs to be streamlined.
- The "Four Pillars" of the Coleman Care Transitions approach are in use in many settings that are not using the whole transitions coaching model. It seems to be a simple way to list and remember critical elements of transitions. (The approach is documented online at www.caretransitions.org/documents/CTI_Summary.pdf.)
    1. Medication self-management,
    2. Personal Health Record,
    3. timely physician follow-up, and
    4. knowing the "red flags" that something is going wrong and how to respond.
- Estimating the patient activation level using a quick interview tool helps target the teaching for self-care to the right receptivity and to help enable the patient to take more of a role. In one Care Transitions site, nearly everyone is brought up to a good level of self-care within a month of hospital discharge. One tool, the Patient Activation Measure, can be obtained by contacting Craig Swanson at cswanson@insigniahealth.com. You must have a license to use this measure. (For documentation on the Patient Activation Measure see: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1361049/)
- Getting multiple parties to agree that they each, individually and collectively, "own" the problems that arise during transitions - and each one has responsibility not only for their

own process but for the meshing with the processes ahead and after theirs. The usual situation is that no one "owns" the period of transfer. One nurse said early in one of the Care Transitions initiatives: "We aren't responsible for them [patients] once they leave!"

- Many improvements are "one person thick," at least for the first months, so that illness or changes in that person's job can send a good idea off track. It is important for the process to be known and owned by multiple persons very quickly.
- Hospital-based clinicians often see the hospital period as the defining element of the course, and post-hospital care is meant to shore up the gains. Outpatient clinicians (and usually the patient and family) see the hospital period as one of many elements that mark the course of living with chronic illness - so there is ALWAYS a need for follow-up and ongoing care.
- For nursing home residents, discussions of limiting hospitalization and resuscitation are often difficult until the resident has been back in the hospital once - and then the hazards of hospitalization are so much more evident that resident and family are more willing to consider staying on-site for most complications.
- The coalitions regularly called for uniform assessment methods, so that patient assessments would be able to be followed across settings of care. Some of the teams were developing their own, and some proceeded to use elements from the CARE instrument, even though CMS had withdrawn it partway into the project.
- Coaching and nurse visits are very expensive elements and not readily done by volunteers or as part of an existing job, so they probably need to be targeted to higher risk, and higher gain, patients.
- In one hospital, the hospitalist on one floor does rounds with the multi-disciplinary team and the patients and families at the same time every day. The effect upon rehospitalization was substantial, even though that was not the initial aim.
- Many fee-for-service physicians do not know the possibilities for billing for services such as reviewing the plan of care with the home care nurse, or having a family meeting with the patient to settle a plan of care.
- Very sick patients often do not learn most of what they are taught - the teaching about self-care usually has to be reinforced once they are home.
- Self-care can be supported with written materials and with videos. One provider has arranged for the instructional videos to be played on the local cable, so patients can watch them at home. Thus, a physician can write a prescription for the patient to view these videos.
- Medicare Part D plans vary substantially in formulary, so that often dictates a change in medication or at least its appearance at discharge. These changes confuse patients and families.
- High rates of readmission afflict dialysis patients, so working with dialysis centers to manage medical issues early seems likely to reduce hospitalizations, complications, and mortality.
- Dyspnea when dying is a major cause of moving a person from community or nursing home to the emergency room. Many physicians are wary of ever using opioid medications in this setting. Only the hospice programs have much skill and familiarity, and even they are not always reliable. So, short-of-breath patients who are not yet in hospice have no real alternative to the ER, and then usually to intubation. A focus on

dealing with dyspnea near death without needing hospitalization would reduce pressures to hospitalize.
- Mapping the process of discharge, transfer, and resettling between the provider partners has been a reliable way to notice problems and get teams focused. Especially when the discussion turns to mention of specific recent patients who shared these providers, the salience of the work becomes clear.
- One team contracted for coaching, thus creating a potential line of work for a consulting business. Others provided coaches within their budget, and some got the providers to establish some coaches if they wanted to pursue the Coleman model.
- One Care Transitions team identified patients at nutritional risk during their coaching and the Department of Elder Affairs for the state and the Area Agency on Aging provided 10 supplemental meals when the person first went home.
- Many hospitals and sometimes other providers have onerous processes for approving forms that go into medical charts - often lasting a year. This makes it important to make changes that do not require changing forms!
- Two Care Transitions teams pointed out that patients have "the right to fail" - that is, they can choose to go home without adequate support, even in a risky situation.

See also The Medicare Transitions Experience.

It takes a village (TOC) > Fixing care transitions > The Medicare Care Transitions Experience

Medicare sponsored a Care Transitions initiative in 2008-2011 aiming to reduce rehospitalizations within 30 days for Medicare fee-for-service patients. (See: http://www.cfmc.org/caretransitions) They authorized the Quality Improvement Organization in each of 14 states to work with local providers to implement evidence-based methods to improve hospital discharge and after-hospital care. This work required ending up with more settled and sensible processes to support elderly people recovering from hospitalization as they move from the hospital to the next place of care. Initial observations worth knowing include:

1. Many providers who share patients sequentially do not know one another or the capabilities of the next care setting. Major gains come from simply getting people to meet, to talk about shared patients, and to build the sense that the providers share responsibility. One participant said: "Getting together in our clusters has become like family!" Another said: "Many of the 'Aha moments' in this project are just to know what happens outside of our facility - it is astonishing how much we just don't know!"
2. Very often, these initial meetings are very awkward, with the different parties having long-standing patterns of blaming the other parties for patient harm and having quite different values and language. For example, the hospitals appear to nursing homes as

being resource-rich and inattentive to costs and to harms like pressure ulcers and delirium, while hospitals perceive nursing homes to have inadequate medical skills in diagnosis and treatment. Usually, sharing in mapping the processes involved in a transfer or telling recent stories about shared patients "breaks the ice" and forges alliances.

3. Most hospital-based providers believe that chronically ill Medicare patients are not financially attractive to the hospital and are therefore willing to set aside what sometimes is intense competition for other patients among hospitals. This is not always true, of course, and longstanding antagonism, competition, or disrespect can require that care transitions work be split up with one coalition per hospital.
4. Even though nursing homes and home care are often even more intensely competitive for "market share," there has been much less challenge in getting multiple providers to share in problem-solving with their hospital(s). Perhaps nursing homes and home care (including hospice) are so much less powerful in the local system that they are willing to cooperate in order to work out standard practices with their referral hospitals.
5. Clinicians often become enthused when frequent patient problems are averted and resolved. They have more "joy in the work" and professional pride. Better patient care is a powerful motivator!
6. Research has established the merits of certain interventions (i.e. the hospital discharge process). (The QIOSC has published information on their results online at http://www.cfmc.org/caretransitions/files/Care_Transition_Article_Remington_Report_Jan_2010.pdf.) Most of the communities chose to implement one or more of these, sometimes with substantial adaptation to local conditions, and others look promising.
7. The measurements in use to monitor improvement are undergoing improvement themselves. Rates of discernible error are probably the most direct and sensitive, though rates of rehospitalization have been most used. Other measures to look are are cost and patient experience.
8. Feedback from downstream to upstream providers is a critical link, but hard to achieve. Many downstream providers feel themselves to be dependent upon the upstream provider for referrals, so they don't want to be seen as complainers. The upstream providers simply never realize that their practices are causing trouble, or the issue arises so infrequently that they assume that a problem arose for an unusual reason (including inappropriate provider behavior at the receiving end). So, one major intervention is to get upstream providers to seek feedback and to protect parties who give useful critiques from adverse action. One team is managing to get feedback on most discharges direct to the QIO, which sums up the quality of transfer and gets information back to the senders about the patterns.
9. Some teams found the schisms in their community too deep to heal in just a couple of years and chose to work with separate competing hospitals in parallel. Sometimes the same pattern of parallel projects arose not from antagonisms and competition but just from lack of interest by the hospitals in working "for the community" rather than for the benefit of the providers and patients who used their hospitals. "Community-ness" is a resource that is not evenly allocated! When one hospital system has been aggressively buying up small community hospitals, the remaining providers may be too suspicious to share work or data with the acquisition leader, a situation that might dictate that parallel coalitions be formed.

10. The sites ended up with quite different basic work structures. For example, some built community working groups that crossed all provider and community boundaries, working on standardization, communication, patient activation, and other broad challenges. Some worked with whole communities but organized around implementing specific proven interventions like Project RED, Care Transitions, or Transitional Care. Some worked with each hospital and its referral group of clinical providers in parallel, with each group only vaguely aware of the others working in the same community. Most governed by consensus rather than any more formal mechanism. Some were moving toward incorporation as non-profit entities, but most expected to continue the work as an informal voluntary coalition indefinitely (or to fade away when the QIO convening the work was no longer available).
11. Social service providers, especially the Area Agencies on Aging, were quite interested, resourceful, and creative. One AAA recruited volunteers for coaching patients, one secured funding for supplemental coaches, and others became valued participants in coalition-building. The AAA have core funding, so they are not direct competitors with clinical providers, but they often are directly providing or coordinating many of the social services for the elderly population. They were very valuable parties to recruit to the work.
12. Coaching to patients was not always accepted by the patients. One site that used older volunteers who had hospital badges and support of the hospital staff had less problem with refusals, while a site that used student volunteers had a great many refusals. Sites that used nurses seemed to have very low rates of refusal.
13. The stronger community coalitions usually included public health officials and representatives of businesses or insurers.
14. Multiple hospitals involved in the Care Transitions theme figured out how to provide EMR information to outpatient and nursing facility partners during the initiative. In some cases, they even provided EMR access to competing hospitals, for patients who ended up in the other hospital's care. One hospital prudently insisted on their partners adopting a formal promise to immediately dismiss any employee found using personal health information improperly, and then they allowed read-only access to the hospital's EMR.
15. One important observation from a ward nurse is that working within the coalition is not much different from working in a hospital with an open physician staff: "You have to convince a lot of people who are able to act independently to develop standards and work together!"
16. Very fragile situations at home call for neighborly support, and the Communities of Care idea has taken off in Colorado with more than 200 individuals being supported by voluntary networks established by Stephen's Ministries and other networks.
17. Some coalitions have developed "universal transitions forms" or checklists to ensure that transition information is complete enough. There seems to be a natural tendency for participants to aim to make one of these standard in a region, so all parties come to expect to complete it as "senders" and to get it as "receivers" in patient transfers.
18. The roles of skilled nursing homes, personal care homes and observation stays in hospitals are very different across the communities. In one community, most Medicare discharges involve personal care homes (either directly or after a SNF stay). In another, about one-quarter of re-use of the hospital are not counting as re-admissions because the person is kept for observation only. Some areas send almost all fragile elderly to SNF before home, others do not.

19. If SNFs are going to keep sicker patients on-site rather than hospitalize them right away, they have to enrich their clinical services to provide safe care - e.g., by having physicians more readily available, or having more stable and clinically well-trained nursing staff. Hospitals often helped by providing trainings and sometimes by doing telephone consults without moving the patient to the hospital.
20. Some teams are finding it important to keep adding participants as the scope broadens and successes accrue. For example, one realized that "care managers" in the hospitals, which were already participating, did not mean that nursing leadership was engaged, and had to backtrack a bit to bring the nursing leaders on board. One team is finding it useful to reach out to the emergency medical system and to community pharmacists.
21. One community had a practice of using home health agencies as technicians for special interventions (like wound care, for example) and assumed that ordering HHA for three visits for wound care required no particular knowledge of the patient, medications, or much else. The discharge summaries and medication lists did not go to the HHAs. The meetings of the coalition have illuminated the shortcomings of this approach and corrected it so that now any ensuing provider will get the basic discharge information.
22. In a couple of sites, having some funded time for one or two staff members to work on piloting the interventions really helped get things moving.
23. In the first 30 patients at one site, 87% had a medication discrepancy at their first after-hospital phone call, and 18% had an additional transition error sufficiently important to require immediate intervention by the nurse making the calls.
24. The QIOs and their partners generated a number of instruments, videos, and checklists that will be useful in future improvement efforts concerning transitions in setting of care. (See: http://www.cfmc.org/caretransitions/toolkit.htm)
25. One team had the "receivers" join in a workgroup, which is gradually leading to the outpatient physicians and providers having more of a voice in discussing priorities and solutions with the hospital. It was curious that they were seen only as "receivers" when they are "senders" also.
26. Standardization is very difficult when each provider is often part of multiple networks - the local system, their own corporate structure which may be multi-state, and their professional peer group that often sets standards.
27. Except in the community where the "receivers" were organized into a working group, it has been difficult to engage practicing physicians in the work of reducing rehospitalization. While this pattern arises in part from time pressures or financial self-interest, it also arises from the paucity of opportunities for physicians to get together with one another - they simply do not have many points of contact or pre-existing organizations that can take the lead in working out the details.
28. One of the Care Transitions teams made major adaptations to the Naylor model (See: http://www.transitionalcare.info/index.html) to have the home care coordinator (full time in-hospital position funded by home care agency) asses all patients before home care discharge to target the ones that are most likely to benefit from transitions coordination. Those patients get a special home care team for their first few visits - a team trained in the Naylor method of coaching, medication reconciliation, and bridging services to home after hospitalization.

29. Medication reconciliation is a major challenge, but so is medication management with a reconciled list of medications. Getting the medications and getting them taken remain challenges, even with a fully reconciled list.

It takes a village (TOC) > Fixing care transitions > Targeting rehospitalization

The Care Transitions initiative for QIOs and many upcoming elements of health care reform target rehospitalization of Medicare patients as a misfortune in itself and as an indicator of a health care delivery system's overall quality of care for sick elderly persons. Since rehospitalization rates in Medicare vary from about 13% to 23% within 30 days it is likely that those areas on the high end are substantially less careful about supporting discharged patients in the community then are those at the lower end. The insights gained from the Care Transitions work and from other work on transitions provide a number of keys to communities that aim to tackle these issues. The Patient Protection and Affordable Care Act (health reform in 2010) has a number of provisions aimed at reducing rehospitalization and exacting penalties on care systems that persist in having high rates. In addition, some insurers, managed care plans, and care managers are beginning to take note of the rehospitalization rate of various providers and using that in selecting advantageous providers.

However, there are some uncertainties that are worth knowing. First, the simple metric of rehospitalization within 30 days turns out to be quite complicated. Should one count "observation stays" in which the patient is back in the hospital but not quite admitted - and can stay in that status for days? Should one count each rehospitalization, even if it is the same person being readmitted many times, or do you only count the first one for each patient? These and other questions illuminate the fact that the extant measures are not yet standardized, and there is little publication on the effectiveness of any of the measures in monitoring progress. Second, the denominator in the rate of rehospitalization is affected by the same practices as the numerator - so, as one provides better care in the community and more continuity and advance care planning, one often sees a substantial reduction in hospitalization itself. Thus, the rate of rehospitalization may not move nearly so much the number of rehospitalizations does, even though improvement is happening.

Indeed, at some very low rate of hospitalization, the rate of rehospitalization might even increase, since the people being hospitalized are down to those who have very fragile health and for whom medical care in a hospital really offers an advantage. Probably, over the upcoming few years, better metrics and benchmarks will be developed.

See also Experience of CMS Care Transitions.

It takes a village (TOC) > Coordination and palliative care

- Advanced illness
- Advance care planning

It takes a village (TOC) > Coordination and palliative care > Advanced illness

In the US, major opportunities for rapid improvement in health care system performance lie in improving care for persons who are living with serious advanced illnesses, often with more than one chronic condition and more than one social problem as well. This is a very costly time of life, with some estimates showing that as much as half of all health care costs fall into the last tenth of most Americans' lives. For most of this time, the person is not seen as "dying," though he or she is already living with the condition that will eventually cause death, perhaps many years into the future.

The health care system seems to concentrate its problems on this part of life. At just the time when continuity matters most, patients often move around in the system with no continuity of provider, records, care plans, or support. At just the time when patients have to manage a large number of medications and treatments, they are given confusing information and they are often cognitively impaired. At just the time when family support is uppermost, the care system rarely assesses the family capabilities or provides training or support. Thus, virtually every community can improve care of the population with advanced illness (in the "Bridges to Health" model, categories 6 (short period of decline to death), 7 (intermittent exacerbations from organ system failure), and 8 (multi-factor frailty) and not only improve the experience of patients and their families and friends but also generally reduce costs. One can provide better symptom management and palliative care, which has been shown to reduce use of costly interventions. (See references provided by the Center to Advance Palliative Care at www.capc.org/research-and-references-for-palliative-care/citations/starter-pack/data-impact-palliative-care-services/index_html). One can simply improve transitions from hospitals and nursing homes to the next setting of care. One can initiate pervasive advance care planning, so that care is aligned with patient preferences.

Obviously, in working with situations in which the patient will eventually die, concerns over rationing care are easily aroused, and the coalition would do well to be sure that their approach really is to inform patients and families of their situation and the options for care and to ensure that good supportive options are at least as readily available as "last ditch" treatment options. It also helps to be clear that the community does not support using unproven and costly treatments but that the community does not aim to ration treatments of proven merit.

It takes a village (TOC) > Coordination and palliative care > Advance care planning

Most people plan ahead for most important things in our lives - marriage, children, college educations. Yet our health care system has become broadly inept in helping people to prepare for the major and foreseeable effects of progressive illness and aging. Advance care planning, in its various guises, aims to correct that lack of planning. The core element in advance care planning is for the clinical care providers to collaborate with the patient and family in understanding the clinical situation and how it is likely to unfold, and then making plans as to how to best live within the constraints of the situation. Advance care planning does not aim to persuade people to accept having only palliative care, nor does the process offer unreasonable certainties about what will happen. It is just a human effort to situate the patient and family to live best with the situation as it really is. Thus, the first elements of advance care planning are honesty and perceptiveness about the situation and its likely course. That does not mean having clarity on the prognosis for survival, but it does mean being honest about what is known and the range of "unsurprising" outcomes. And it also means that the clinicians have to know what services that might make a difference are actually available to this patient and family. No one benefits if the physician and family expect that a person can stay home with sedation during a death from lung disease, but the local hospice and home care agencies cannot provide sedation quickly!

There are various projects working on community-based improvements in advance care planning. Probably the most helpful to get started are Respecting Choices (respectingchoices.org) a program initiated in La Crosse, Wisconsin and proven to achieve nearly universal advance care planning before death, and the POLST (Physician Orders for Life-Sustaining Treatment) (www.ohsu.edu/polst), a multi-state endeavor to communicate the bare essentials about patient preferences as the patient moves around in the care system. Other projects are likely to be underway in your state, and your palliative care and hospice providers will be abreast of these.

It takes a village (TOC) > Pointers and Tips

- Testing
- Overcoming challenges - How can we fail?

It takes a village (TOC) > Pointers and Tips > Testing

Every once in a while, the best thing to do is to raise money, make plans, get permissions, recruit staff, and implement a new program. But mostly, this approach is a dead end in improving health care systems or promoting health. It is much more likely to be effective and sustained to use the methods of continuous quality improvement (CQI), which is a much quicker and more effective method than implementing programs. One key strategy is to learn to test ideas first, rather than implementing them broadly.

How do you do that? Imagine that you or someone else in your coalition has what sounds like a really good idea - sounds like it would really help solve some ongoing problem. For many people, the initial instinct is to figure out how to get it implemented. Resist that! First figure out if there's a way to test it out, perhaps in a couple of ways, before lining up behind it. If someone wants to get the POLST used in all the nursing homes in the community, see if there's a way to get one nursing home to try it out on one unit, or to get a hospital to use it for the next half dozen people discharged to a nursing home. Talk with the testers - what was awkward, what caused delays, what problems appeared - and did they have the sense that it was worth doing!

Then adapt your intervention to your community. Sometimes you gather a lot of support by changing a few words, giving a form a different heading, or reassigning responsibility to a different person who is eager to take it up. And then test it again! Perhaps this time a bit larger - include another nursing home, or another kind of patient. Gather stories, fix things, and get enthusiasm going. Measure how you are doing - what is the uptake, how long does the process take, does the new resource get used?

If you keep expanding the scope, at some point you are not really testing the intervention but its ability to spread and to be sustained, and those achievements require thinking ahead, being ready to build enthusiasm and overcome resistance, keeping work within the capacity of the people and other resources, and building in steps that make backsliding hard. With the POLST, you could put success in the newspaper and local TV, making non-compliance risky. You could gradually establish having a high rate of POLST be something to report on provider comparison websites, or otherwise make it a standard of practice. You can make sure that the emergency medical services providers are comfortable with their instructions and integrate that teaching into their training.

It takes a village (TOC) > Pointers and Tips > Overcoming challenges - How can we fail?

What are the pitfalls and barriers? Some are obvious, but some might surprise you. Experience thus far reveals these sorts of problems:

1. Too fragile a coalition - can't actually get participants to implement change, can't set priorities - dysfunctional governance often arises from requiring complete consensus or proceeding with fragile majorities (See: Governance of community coalitions)
2. Coalition dominated by one party that acts on its power, creating distrust (See: Ostrom's Model)
3. Overbroad scope - it is always overwhelming to take on all issues that affect health and well-being - start with a narrow scope and expand to a reasonable scope that reflects the mission of participants - don't impose an obligation to work on everything
4. "Project" orientation rather than long-term planning - funding from grants and contracts and mandates from executive officers often require thinking of the work as being dominated by projects with a proposing phase, a start-up, and then an evaluation and conclusion phase. Then they are done. Using these project opportunities to build toward overall strategic goals is important, and rare. The "project" orientation gets in the way of building toward fundamental improvement through ongoing learning and changing culture. (See: Tale: we fixed that) Instead, build a learning environment that values testing
5. Coalitions can be greatly hampered by individual participants who are personally disruptive and offensive or who cannot bend to collaborate with others. Coalition leaders will have to set rules that limit the harmful effects upon the process and other participants, including sometimes making arrangements with the problematic party to have a little piece of their agenda and in return not to disrupt the rest.
6. Difficulty with time - either letting change take so long that everyone loses interest, or setting time frames that cannot be met. The art of keeping pressure on change by setting strong goals without making them disheartening by guaranteeing failure is difficult.
7. Antitrust - there is a pervasive concern that working together across competing businesses will violate antitrust laws. At present, there is no evidence of this concern actually coming to pass, but it remains a concern and some parties are working to define the risks and provide information.
8. Research rules - sometimes innovation gets mired in the deliberative process that has been put in place to review research involving human subjects. Figuring out whether an initiative actually counts as research is important, and engaging the research review to include improvement activities usually slows down both activities to no good end. A substantial consensus process yielded an authoritative discussion of the issues and a briefer action guide, though the issues are still unsettled.

It takes a village (TOC) > Stories

- Tale: Too many med lists
- Tale: We fixed that

It takes a village (TOC) > Stories > Tale: Too many med lists

One meeting of skilled nursing facilities in an area yielded a strong complaint that some were routinely hit with multiple medication lists from the hospital, rather than the usual complaint of getting none or an inadequate one. The problem was that they did not match, and it was usually not possible to tell which one was the definitive one. The SNFs present felt that this was the hospital's fault: the nurse who was doing the admission faced these multiple lists and could not figure out the right one. The QIO staff found this problem intriguing and started to investigate. It turned out that the hospital was usually generating two lists - one with the admission application and one just before discharge that came with the patient. Once a person could identify these two, they were easy to distinguish, even though they might be dated on the same day. The admission application version was always faxed by the social worker at the hospital, and the final version was faxed by a nurse who added by hand a notation as to which ones had been given. This much made sense.

But there were usually two more lists - where were they coming from? It turned out that one had been sent by the SNF's own representative in the hospital when she checked on the patient before the facility accepted the potential admission. This one could look just like the admission application (though often with different medications listed). And then there was one more, which arose because the SNF had access to the electronic medical record, so the admissions director routinely printed one off on her own. Obviously, there are ways for even a couple more to show up - e.g., if one was faxed at the time of discharge and a hard copy was sent along with the patient.

One might think this did not matter, since the SNF could just look at the hospital EMR, but the SNF nurses pointed out that it is not uncommon for the doctors to decide to change something about the discharge medication list at the last minute and not to enter that decision as an order, since it will not be executed in the hospital. For example, a doctor might say in a final meeting that the patient should cut the dose of Coumadin in half on the basis of this morning's lab tests, and properly enter that on the discharge medication list, but never enter it in the hospital records.

Once the SNF staff accepted their part of the blame, they started working on reducing the confusion. The two lists from the hospital seemed worth having, but the SNF started being sure of the time things were faxed and agreeing to use only the final one for patient care. The version from the liason nurse was really duplicative and used only to be sure that the admission version was complete. So, the admissions nurse started to mark it as a duplicate as soon as she had reviewed it. If anyone downloaded a version from the medical record, the printer was set to note the time, and it was not faxed, so it stopped causing confusion.

There still could be concerns - if a medication was altered at the last minute without clear documentation, it could be unclear to the nursing home physician whether the decision really had been made. Thus, the hospital staff were asked to add a note to the electronic medical record that explained any last minute changes. Without that, they agreed to prioritize any call-back from the SNF to confirm a change that was only noted by hand on the discharge medication list, or only related by the patient.

This process turned up an additional concern: hospital lists do not generally include medications taken at long intervals (e.g., once per month), self-administered eye drops or skin lotions, or long-standing "as needed" pain medications. The teams had not started to address these concerns yet, but it clearly was going to be mainly the SNF task to figure them out, with the patient and family.

This tale illustrates:

- Just how complex medication reconciliation really is, even though this story addressed only how to get a definitive list from a hospital to a nursing home and how to make it error-free,
- How easy it is to assume that a problem arises from someone else's procedures rather than your own,
- How duplication of information is not a lot better than paucity of information,
- How important standardizing practices can be, both practices like labeling the medication list and practices like documenting even the changes made at the last minute.

In addition, medication reconciliation was reported to be complicated by having different formularies in the different settings (hospital, nursing home, and home, for example). Some years ago, Vermont made a statewide accord about how to treat symptoms in persons nearing death. Compliance was voluntary and not enforced, but if the physician would order the medications on the guidelines, everyone could count on every pharmacy being able to deliver the medications, every nurse in a nursing home knowing those medications, and even mostly having no changes for the patient just because they moved from one setting to another. Standardization is often more important than having lots of choices!

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One hospital drawn into the Care Transitions work had already done a project to implement a published discharge checklist and the staff and leadership were proud to point out how far ahead of the curve they had been. However, the Quality Improvement Organization involved was hearing from the home health agencies that they were quite dissatisfied. The home health agencies were not willing to tell the hospital about their problems, for the usual reason of not wanting to make themselves undesirable for referrals. When the QIO conveyed the concerns, the hospital leadership said they must be wrong. But one of the principles of good improvement work is to be willing to measure the performance, and the QIO was able to document that multiple conflicting medication lists were routinely coming to the home health agency and that it was very difficult to find someone willing to resolve the issue, once the patient had left the hospital. While it was painful to have to revisit a process that leadership thought had been optimized, it was essential. The checklist was perfectly adequate from the hospital's standpoint, but they had not thought to check its performance where it most mattered - with the downstream providers.

This illustrates:

- The value of evolving a process, rather than implementing a program,
- The value of testing in small samples before broad implementation,
- The merits of measuring outcomes, not just implementation,
- The need to work across provider boundaries,
- The use of a third party to provide feedback to the hospital without fear of retribution,
- The need for the hospital to seek feedback and to make it safe to give feedback,
- The nature of a dysfunctional situation that puts patients at risk,
- The danger of being proud of a situation without measuring its real performance.