

Conceptualizing, Implementing, and Evaluating

Extended Care Pathways

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National Chronic
Care Consortium**

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Introduction

The Move Toward Integrated Care

The development of integrated health care networks is one of the more dramatic trends in health care delivery in the 1990s. Integrated networks are expected to contain costs and improve care by providing consumers with a seamless continuum of services. In truly integrated networks, all components of the system work together to maximize client outcomes and system effectiveness. Regardless of the specific setting in which care is received, clients experience their care as an integral part of an overall plan that maximizes health, wellness, disability prevention, and client satisfaction.

Integrated networks address a well-recognized flaw in the current health care system—fragmentation. A fragmented care system is one in which different components of the health care delivery system (e.g., different providers, different professionals, different funding sources, different information and communication systems, different administrative structures) work independently of one another, and often at cross purposes. Fragmentation results in the duplication of services in different settings, inappropriate care when the treatment of one provider interferes with the treatment of another, and cost shifting as each setting independently tries to contain its own costs. In addition to adversely affecting quality and cost control efforts, fragmentation makes it difficult for consumers to understand what services are available to them, at what cost, and how to easily access the services they need.

While the concept of integration is espoused by an ever-widening body of providers, consumers, researchers, and policy makers, implementation of the concept remains an elusive goal. Exactly what is integration, and, in practical terms, how can it be achieved?

Role of the National Chronic Care Consortium

The National Chronic Care Consortium (NCCC) is a national organization of twenty-four (24) health care networks dedicated to answering these questions and improving the integration of chronic care services. The NCCC's focus is on "chronic care" because chronic care is the fastest growing and most expensive component of the health care system. Overall, 11 million persons over age 21 have severe and chronic mental and physical impairments, with costs exceeding \$100 billion in the public sector alone (Center, 1994). The current health care system, with its strong focus on acute care, has not adequately served persons with chronic conditions. The NCCC's focus is on "integration" because fragmentation is an especially serious problem for persons with chronic illness. These individuals typically need a wide range of services from many different providers, setting the stage for fragmentation and making integration imperative.

Extended Care Pathways

The NCCC is working to improve the integration of chronic care services in a variety of ways. This document presents the results of one of the NCCC's most important areas of focus — extended care pathways. Extended care pathways are an important technique for integrating care management for persons with chronic conditions.

Simply put, an extended care pathway (ECP) is:

a set of policies and procedures that providers use to address a specific disabling chronic condition over time and across various service settings. It is a standardized approach to the multidisciplinary care of an individual with a particular diagnosis.

Extended care pathways are designed to increase continuity of care between settings, and thereby improve both the quality and the cost-effectiveness of care. In today's fragmented health care system, where a person with a chronic illness can be sent from one care setting to another with no real continuity between providers, extended care pathways offer a means of increased provider communication and collaboration.

More specifically,

extended care pathways specify what will be done, at what particular points along a specified time scale, in order to achieve the desired outcome. An ECP represents a consensus of expectations for a setting and diagnosis. It is intended to be used as a tool for managing, monitoring, and evaluating care.

Extended care pathways are related to, but different from, the more familiar tool of "critical pathways." Critical pathways are "abbreviated versions of case management plans. They show the critical or key incidents that must occur in a predictable and timely fashion to achieve an appropriate length of stay (in a hospital)" (Woldum, 1987). Both critical paths and ECPs are tools used in tracking and optimizing an individual's health and functional well-being. Both critical and extended care paths indicate what key events are necessary for individuals to meet expected outcomes. The major difference between the two types of pathways is that ECPs are expected to apply to the entire course of a condition and the full continuum of care; critical paths, in contrast, generally pertain to the services provided to an individual by one provider, for one episode of care.

ECPs are in a state of evolution (see Table 1). In the "first generation" of ECPs, general concepts are articulated and ECP components are developed for different settings and diseases (e.g., pathways for home care, hospital care, and nursing home care for a person with Alzheimer's disease). In the "second generation," a continuous ECP extends across the entire course of a condition and related care settings, clearly showing the links between settings and how care received in one setting can enhance the cost and quality goals established in another setting. "Third generation" ECPs concentrate on documenting and improving ECP outcomes, continually working on implementation issues, and addressing complex issues such as how paths are used in cases where several chronic conditions exist simultaneously in one individual. At this point, NCCC sites and others are still developing "first generation" ECP products, with uneven movement toward generations two and three.

Table 1: The Evolution of Extended Care Pathways

ECP Precursors	First Generation	Second Generation	Third Generation
Care management and other practices promote continuity of care across settings.	ECP concepts and implementation strategies are developed.	ECP concepts and implementation strategies are refined (e.g., making paths user-friendly, resolving language and other differences between settings when creating a continuous ECP).	ECP concepts are commonly understood and used by providers.
Critical paths are developed in acute care settings.	Separate ECP components are developed for non-hospital settings (e.g., an ECP for adult day care).	Continuous ECPs (i.e., an ECP that extends across all settings) articulate how different settings work together to achieve common quality and cost goals.	ECP outcomes are tracked and improved upon in a CQI process.
Critical paths are developed for acute diseases.	Separate ECP components are developed for an expanding number of chronic conditions.	Continuous ECPs are used across settings, expanding to new areas of chronic illness such as pain management and care of the frail elderly.	Numerous complex ECP issues are addressed, answering such questions as: - How can ECPs best be used with co-morbidities? - What are the legal implications of ECP use?

Extended care pathways are but one strategy for integrating services and care management. Other care management strategies emphasized by the NCCC include: simplified client access to services across settings, streamlined transitions between settings, and a physician/care management team that provides centralized care management.

Extended care pathways are being implemented in over half of the NCCC's sites. NCCC members have found ECPs to be helpful in integrating care on behalf of persons with chronic conditions and are in the process of documenting the effect of pathways on care and costs. This document is designed to share the NCCC's experience with extended care pathways, advancing the state of the art within the NCCC and among other provider sites interested in improving the continuity and cost-effectiveness of chronic care.

In Section 1, the antecedents of extended care pathways are described, including clinical care guidelines, critical pathways, and psychosocial case management. Section 2 presents a conceptual framework for extended care pathways, while Section 3 provides guidance on how to make ECPs operational in a chronic care network. In Section 4, two NCCC sites (Lutheran General HealthSystem and St. Mary Medical Center) provide case studies of ECP development and implementation, highlighting practical strategies for success and potential sources of problems. Section 5 illustrates the purpose of ECPs — to make a real difference in patient care — by describing a case of a client whose experience with the health care system could have been vastly improved through the implementation of extended care pathways and other integration strategies.

Extended Care Pathways in the Context of Fully Integrated Chronic Care

The NCCC's development of extended care pathways is best understood within the context of the NCCC's overarching goal of establishing chronic care networks (CCNs). A CCN is a system of care that

meets the unique needs of persons with chronic conditions by integrating care over time and across settings. The NCCC and other organizations working to establish integrated networks recognize that integrated care is an essential but not sufficient element of full integration. Other care management strategies emphasized by the NCCC include: simplified client access to services across settings, streamlined transitions between settings, and a physician/care management team that provides centralized care management. In building fully integrated chronic care networks, the NCCC seeks to develop all of the following:

- **integrated care management**, where sources of care management are linked to assure that care provided in different settings, at different times, and by different professions in the network on behalf of clients all support common client and system outcome goals (e.g., through the use of extended care pathways);
- **integrated systems management**, where network management assures that key executives, professional leadership, and network personnel are working to support common client and system goals across all service settings;
- **integrated care financing**, where all components of the network's financing system support integrated, appropriate, and cost-effective care delivery;
- **integrated information systems**, where network information and communication systems link decision-makers at all levels of authority and in all settings with core information to support common client and system goals; and
- **integrated public policies**, where state and federal policies support integrated chronic care.

The NCCC has developed materials that describe the chronic care network concept and the above aspects of integration in some detail. The NCCC is also creating tools and demonstration activities to promote success in building integrated chronic care systems (see Appendix A).

Section 1: Antecedents of Extended Care Pathways

This section briefly discusses developments in medical, nursing, and psychosocial arenas that preceded the emergence of extended care pathways (ECPs). ECP antecedents include clinical care guidelines, critical paths, and psychosocial case management (Kelly, 1992; White, 1995; Zander, 1988).

In examining these areas, it is important to note that the nomenclature surrounding care management and standardized practices is still evolving and sometimes unclear. Terms such as “practice parameters,” “clinical guidelines,” “clinical pathways,” “extended care pathways,” and “case management,” for example, can be used by different persons and organizations to mean different things. The NCCC's definition of several key terms is found in this section and in Section 2; Appendix B provides a glossary of terms.

Clinical Care Guidelines

Clinical care guidelines, alternatively called protocols, practice parameters, or medical-oriented guidelines, are:

a consensus-driven standard for clinical care. They describe, usually in narrative form, what is appropriate, effective care. This is frequently based on a review of research findings and/or the experience of a panel of experts. Guidelines usually cover one profession and are not specific to a setting, an individual, or a timeline.

Clinical guidelines have been part of the medical literature for more than 50 years. In the last decade, interest in guidelines has been significantly renewed, due in part to the growing body of evidence that much of medical practice varies according to individual practitioner preference and style, rather than according to what type of care is documented to be most effective in meeting desired outcomes (see Chassin, 1986). Guidelines are expected to assist providers in standardizing care across physician settings and basing treatment on improved outcomes.

Limitations

In recent years, pointed questions about the scientific soundness of guidelines have come from physicians, third-party payers, and patients. One limitation of guidelines is that they have been narrowly defined and address only a point in time. They typically identify acceptable strategies to assist physicians in making clinical decisions for a certain condition, but with few exceptions, the guidelines do not address disease progression and intervention over time. In most cases medical guidelines have been physician-based with little input from non-physicians. Also, guidelines have typically focused on younger populations and acute conditions. A recent random sample from the AMA Directory of Practice Parameters, for instance, found that “only a minority of practice guidelines contain information about older persons ... rectifying this lack of knowledge is imperative as the population ages” (Rudberg, 1994).

Recent Developments

In response to the historic limitations of guidelines, physicians and physician organizations have established groups to guide, coordinate, and improve them. The Agency for Health Care Policy and Research, for example, has produced guidelines for 15 conditions and is in the process of developing more (Utilization Management, 1995). These efforts demonstrate the growing credibility guidelines have among practitioners and researchers. Increasingly, issues involved in guideline development relate to refining existing guidelines, expanding the number of conditions to which guidelines apply,

making guidelines more “user friendly” for physicians and care teams, and addressing liability issues (e.g., what happens if a physician chooses not to follow a parameter for sound medical reasons?).

Critical Pathways

The NCCC defines critical pathways as:

care pathways used in an acute care hospital setting. A care pathway is a standardized approach to the multidisciplinary care of the individual in one particular setting with a particular diagnosis. It is an outcome-oriented, consensus-derived agreement, specifying what will be done at particular points along a specified time scale in order to achieve the desired outcome.

Critical Paths Evolved in Hospital Nursing Departments in the mid-1980s. At that time, the prospective payment system and the growth in managed care prompted many nursing departments to cut budgets and reduce staff. At the same time, patient care was becoming more challenging. Patients were being discharged sooner, speeding up the care, yet care was more technical. Nurses had to coordinate care with multiple doctors, sometimes finding themselves caught between physicians who disagreed or wrote conflicting orders. While hospital administrators expected nursing staff to reduce lengths of stay, nurses were often at odds with physicians who wanted to keep patients in.

Most nurses were not prepared to assume 24-hour accountability, nor were they prepared to coordinate care in a complex, fast-paced environment characterized by multiple physicians, shorter lengths of stays, sicker patients, high-tech care, and increased patient loads. It is not surprising that by the 1990s most nursing departments were introducing new delivery care models to manage these changes.

The New England Medical Center

The New England Medical Center was a leader in testing these new delivery models; specifically, the Center developed new nursing case management strategies and originated the critical pathway concept. In the 1980s, the Center's case management program divided staff into case managers and associate nurses. Both provided nursing care, but the case manager was accountable for coordinating care for a specific group of patients and for specific clinical and financial outcomes. This model also paired the case managers with specific physician groups, promoting better communication and collaboration with the primary physician.

Key to this model was the use of critical paths for planning, tracking, assessing, and changing patient care according to established outcomes. Critical paths outlined the medical and nursing care within appropriate time frames. Having every provider follow the same established plan of care eased the coordination efforts of the nurse case manager. It also allowed clear documentation of both clinical and system problems. Clearly, this was a tool that had much more utility than the nursing care plan.

Implementation of Critical Paths

Throughout the country, many health care providers have not readily embraced the concept that medicine needed standardized care. Although numerous hospitals jumped on the critical path bandwagon, the transition has not been a smooth one. Many advocates of critical paths have been accused of trying to practice cookbook medicine and control physicians. Others have found that critical paths are developed and then put on the shelf or implemented incorrectly. Most hospitals view their limited success as a learning experience for the future. Nevertheless, nursing care pathways continue to be developed and their utilization is growing (see *Hospital Case Management*, 1995).

The most important lesson that nursing managers have learned during their journey with case management and critical paths is to include all the disciplines in the development process. New versions of care pathways are much more interdisciplinary. Most hospitals have combined the critical path with the nursing care plan. Nursing has learned to collaborate and negotiate, and to collect, analyze, and report information, including information on activities that take place before and after a hospital stay. Increasingly, the need to focus beyond the hospital walls when developing tools such as pathways is being recognized by the nursing profession.

The Psychosocial Model of Case Management

Extended care pathways are in part an outgrowth of the psychosocial model of case management; in both cases there is a client-focus to the work and a strong acknowledgment of the need to provide continuity of care across settings, over time, and across disciplines. Psychosocial case management is part of a system of care that has operated outside of the acute care facility, complete with its own provider networks, case managers, and reimbursement structures. The NCCC defines the basic function of case management as:

to locate and coordinate care from a variety of resources in response to identified need. Client goals include maximizing independence, providing choices, and enhancing functioning.

Case management was primarily established by professionals with psychosocial orientations as part of community-based systems designed to keep functionally impaired and disabled adults healthy and independent. Most of the community-based programs have focused on individuals with chronic problems, linking them to in-home, community-based, and institutional care. These programs have often assumed responsibility for the care of their clients over long periods of time—sometimes years if no natural support systems existed. Case management has been the linchpin of care in these types of cases by coordinating a wide range of formal and informal services in a cost-effective manner, and by monitoring clients' care and health status before, after, and between acute episodes.

Early Models

Case management as a service delivery approach became an integral part of early public sector national demonstration programs such as the Channeling Projects and the 2176 Medicaid Waiver Projects. These projects were designed to provide in-home and community-based services as alternatives to costly and less desired institutionalization. These types of projects helped to define case management functions, processes, and procedures.

Early on, a major emphasis in case management was the development of instruments to assess a full range of psychosocial and health problems. These instruments were designed to assist case managers in determining the most appropriate care plan for each individual. Case management teams of social workers and health professionals then worked to implement the plan to facilitate cost-effective, in-home care that obviated the need for expensive nursing home care. The coordination of services required knowledge of available resources and the ability to purchase or otherwise acquire them. Monitoring the plan and client status over time required the capability to track information and determine whether the desired outcomes were achieved.

The Importance of Assessment Tools and Information Systems to Pathways

The assessment, care plan, and information tracking development efforts were important forerunners to the formulation of extended care pathways, since they attempted to standardize information and guide case managers toward similar, if not uniform, practice. The quest for the perfect assessment tool has long received the attention of many academicians and practitioners, as has the recording and tracking of care plans and monitoring activities. Information systems development for coordination of non-

medical services has been slow, inconsistent, and proprietary, indicating a need for much more work in this area.

Conclusion

The development of extended care pathways provides an opportunity for the medical, nursing, and psychosocial arenas to converge on behalf of those in their care. Each discipline's expertise contributes to meeting care goals, including improved outcomes. Integrating documentation systems will greatly assist in tracking variances from expected procedures and outcomes. Moreover, meaningful data will help convince administrators and physicians of needed changes in practices and procedures.

Many attempts have been made over the years to link acute care with the community and long-term care systems. Nonetheless, these systems continue to function in parallel with virtually no shared financial resources, common information systems, or coordinated care across services and settings. Integration of these systems has become a necessary goal. Care management, incorporating mechanisms such as extended care pathways, holds great promise for forming the missing bridge.

Section 2: Conceptualizing and Operationalizing Extended Care Pathways

This section addresses the basic definitions and concepts underlying extended care pathways, focusing on the concepts of the health status cycle and disability prevention. Following this discussion, this section presents the basic format and standard components of ECPs.

Defining Extended Care Pathways (ECPs)

According to the NCCC, an extended care pathway is:

a set of policies and procedures for addressing disabling chronic conditions. An ECP represents a consensus of expectations for a setting and diagnosis: it specifies what will be done, at what particular points along a specified time scale, in order to achieve the desired outcome. An extended care pathway is a **standardized approach** to the multidisciplinary care of an individual with a particular diagnosis.

An ECP for Alzheimer's Disease, for example, would show the types of services an individual with the disease should receive over the entire course of the disease, including primary prevention and screening.

Care pathways are **jointly developed by all care providers** to address the **risk factors and care needs of a person with a specific condition**. Pathways identify expectations about the entire continuum of care, including transitions from one setting to the next. Ideally, an extended care pathway is extensive enough to specify care from the first appearance of symptoms to death from a given condition. Minimally, a care pathway must encompass two settings (including the transition between them and the transition from one source of funding to another) to qualify as an "extended" care pathway.

The goal of an ECP is **disability prevention**, to enable providers who serve the same person to collectively prevent, delay, or reduce the onset of (or ongoing effects of) disability throughout the natural progression of pathology, impairment, functional limitation, and disability, across time and place.

ECPs as a Tool for Integration

Extended care pathways are powerful tools for integrating care across service settings. ECPs assist providers in integrating care by providing a conceptual framework for a holistic approach to care planning and financing, identifying responsibilities and authorities related to care management, developing integrated care management policies, and supporting consumer-focused care and prevention practices across settings and over time. ECPs assist providers in meeting care management goals by directly addressing many of the sources of fragmentation seen in today's health care system. Examples of the impact of extended care pathways on barriers to integrated care are shown in Table 2.

Table 2: Extended Care Pathways as a Mechanism for Integrating Care

Barriers to Integrated Care	Impact of Extended Care Pathways
Reimbursement for chronic care occurs through multiple funding sources.	ECPs provide a conceptual framework for capitation that covers all settings over an extended period of time.
Differing cultures of care exist in acute, long-term, and other care settings.	ECPs provide a conceptual framework that includes acute, long-term, and other care. This promotes understanding between settings and enhances cooperation among providers at various sites.
There is no recognized authority for managing integrated care.	The ECP is the authority for integrating care. It identifies the responsibilities of various care providers.
Information systems do not cross boundaries of care settings.	ECPs create the structure within which information is collected and shared. They create the immediate and recognized need for shared information across all care sites.
Case management policies reinforce fragmentation.	ECPs force the development of integrated care management policies.
Consumers focus on the short-term.	ECPs include the consumer in the movement to a long-range focus.
System incentives reward treating illness rather than preventing illness and disability.	ECPs provide system support for prevention. They demonstrate the need for appropriate financial incentives.

Paradigms Underlying ECPs

Client-Centered Care

An underlying concept of ECPs is that the central perspective for ECP development is the person known as the “consumer,” “patient,” or “client.” This perspective is not time-limited, not subject to the biases implicit in particular health care settings and funding sources. Conceptually, this perspective fosters concern with the person’s health from before birth to death.

A client view provides a unified perspective from which to view the whole health care arena, facilitating the development of the pathways that bridge both acute and long-term care. From the client’s perspective, changes over time are experienced as transitions in health status, not just as transitions from one care setting to another (e.g., acute inpatient to extended care) or from one eligibility status to another (e.g., Medicare to Medicaid).

An individual’s “health” is a broad concept as used in ECP efforts and as defined by the World Health Organization. It refers to “a state of complete physical, mental and social well-being and not merely the absence of disease.”

In addition to a client-focus, the paradigm used by the NCCC as a foundation for ECP development has two essential features: the **health status cycle** and the **prevention of disability**. The NCCC’s work in this area draws upon earlier efforts completed by Buchner and Wagner (1992) and the Institute of Medicine (1991).

Health Status Cycle

In the health status cycle model, health status is reviewed in five progressive stages: asymptomatic, symptomatic, functional decline, functional recovery, and adjustment. (See Table 3.) Different stages are associated with different client goals, medical issues and psychosocial issues. For a symptomatic person, the first medical response is to diagnose and then initiate treatment (if appropriate). The psychosocial response to this status is to reduce barriers to compliance with treatment (e.g., ensure the person has transportation to the follow-up medical appointment).

Table 3: The Health Status Cycle

Asymptomatic	Symptomatic	Functional Decline	Functional Recovery	Adjustment
I. Description of status: Asymptomatic, perhaps healthy	Appearance of symptoms	Intense symptoms resulting in loss of function	Process of regaining function	<ul style="list-style-type: none"> • Maintain achieved function and health • Adapt to permanent changes
II. Client Goal: Achievement and maintenance of healthy lifestyle	Compliance and self-management of treatment regimen	Active participant in medical care and recovery	Active participant in restoration	<ul style="list-style-type: none"> • Adjust lifestyle to adapt to functional limitations • Resume social roles • Achieve and maintain healthy lifestyle • Self-manage health conditions
III. Medical Issues: General prevention schedule, with screening	<ul style="list-style-type: none"> • Diagnosis • Start treatment of condition • Prevent progression of disease or disability 	<ul style="list-style-type: none"> • Intensify treatment • Stabilize medical problems • Prevent complications 	<ul style="list-style-type: none"> • Restorative care rehabilitation • Prevent limitations to recovery 	<ul style="list-style-type: none"> • Maintain achieved health and functioning • General prevention of other conditions
IV. Psychosocial Issues: <ul style="list-style-type: none"> • Health education • Public health 	<ul style="list-style-type: none"> • Reduce barriers to compliance • Facilitate choices in care and treatment 	<ul style="list-style-type: none"> • Help with response to illness • Address family problems • Make home available as care setting • Information on choices 	<ul style="list-style-type: none"> • Reduce barriers to compliance • Enhance home and family as care setting • Plan transitions 	<ul style="list-style-type: none"> • Facilitate continued compliance • Supply and coordinate supports for person and caregiver • Assist in adaptation of lifestyle

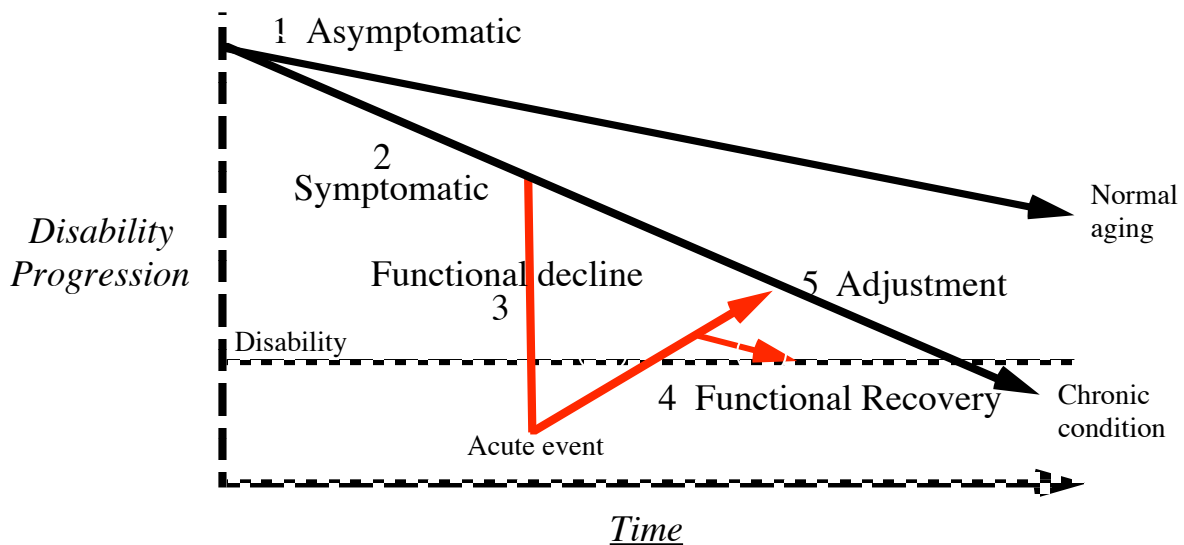
Persons at different stages in the health cycle also require care in different settings. (See Table 4.) A person experiencing a stroke, for example, would have a status of "functional decline." During the asymptomatic stage, this individual should have been treated in a variety of outpatient settings (e.g., for periodic blood pressure screening and encouraging a healthy diet) and during the symptomatic stage, a mixture of inpatient and outpatient settings would have been appropriate (e.g., for treating high blood pressure and high cholesterol).

Table 4: Settings of Care Typically Related to a Health Status Cycle for Stroke

Health Status Cycle					
	Asymptomatic	Symptomatic (e.g., cardiovascular disease)	Functional Decline (e.g., stroke)	Functional Recovery	Adjustment
Typical Setting of Care	MD office - general prevention schedule Health education provider Wellness clinic Health club Membership group of hospital, health network, or managed care organization Public health offices Home	MD office ambulatory care Nursing home Geriatric evaluation service Home	Hospital MD office ambulatory care Nursing home Home	Hospital/rehab unit Rehab hospital Extended care facility Skilled nursing facility Outpatient therapies Day health Home health Home	Home care • Personal care, home maintenance • Respite care Congregate care Nursing home MD office Day care Stroke support group Caregiver support group Senior center Home

Health Status Progression: The dynamic nature of the health status cycle is illustrated in Figure 1. According to Buchner and Wagner, the normal aging process involves a general decline in functional ability, with the possibility of a health event or intensification of existing symptoms leading the individual down a path toward significant dependence. The NCCC has modified the diagram by labeling sections of the trajectory that might correspond with the established health status periods.

Figure 1: Health Status Progression



SOURCE: NCCC, illustrated by R. Bringewatt, T. Holt, and B. Schneider as adapted from Buchner, David M. and Edward H. Wagner, "Preventing Frail Health," Health Promotion and Disease Prevention, Figure 2, Vol. 8., No. 1, February 1992.

The point at which symptoms appear, the point at which symptoms intensify, the steepness of the decline, the depth of the decline, the amount of recovery needed, and the maintenance of the recovery will all vary greatly. Figure 1 could illustrate a condition such as stroke, with a period of sudden functional decline and a potentially strong recovery. For a condition such as dementia, a line could be drawn showing that the period of functional decline may be long and gradual, and that functional recovery may be limited. At each of these points, the individual's status is potentially amenable to modification by focusing on disability prevention.

Prevention of Disability

While the health status cycle provides the health maintenance perspective, the prevention of disability concept provides the framework underlying intervention. This concept encompasses both the "cure" mandate of acute care and the "maintenance of function" mandate of long-term care in an integrated, intervention-oriented philosophy. It also describes the mechanism underlying the threats to a person's health and identifies the action necessary to achieve the *overarching goal of disability prevention*.

The disability prevention approach is well-described in two publications from the Institute of Medicine (IOM). In *The Second Fifty Years: Promoting Health and Preventing Disability*, the authors state:

To accommodate the changing needs of an increasingly older society, we must broaden the traditional goals of health—curing disease and preventing its occurrence—and include preventing the ill from becoming disabled and helping the disabled cope with and prevent further disability. Dealing with disease must include dealing with the consequences of disease (IOM, 1991).

In another 1991 publication titled *Disability in America: Toward a National Agenda for Prevention*, the IOM presents the framework the NCCC has adopted in organizing its approach to preventing disability. This framework establishes four states of progressive disability: pathology, impairment, functional limitation, and disability. These states are defined and summarized in Table 5.

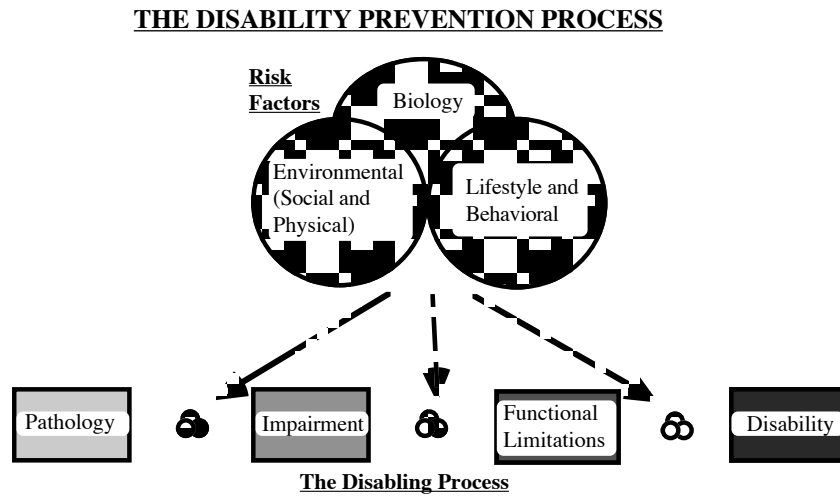
Table 5: Four Degrees of Disability

State: Pathology	Impairment	Functional Limitation	Disability
I. Description of Dysfunction: Interruption or interference of normal bodily processes or structures	Loss and/or abnormality of mental, emotional, physiological, or anatomical structure or function	<ul style="list-style-type: none"> • Restriction or lack of ability to perform an action or activity in the manner, or within the range, considered normal • Results from impairment 	<ul style="list-style-type: none"> • Inability or limitation in performing socially defined activities and roles expected of individuals within a social and physical environment • Results from interaction of physical and mental limitations with environmental factors
II. Location of Dysfunction: Cells and tissues	Organs and body systems	Person — physical, intellectual, emotional and/or social functioning	Society — the person's interactions with her or his world
III. Illustration of Stroke: Changes underlying hypertension and heart disease	Stroke: neurological impairment resulting in paralysis or paresis, cognitive deficits, vision deficits, aphasia, perceptual deficits	<ul style="list-style-type: none"> • IADLs • ADLs • Mobility • Communication • Emotional functioning • Social functioning 	<ul style="list-style-type: none"> • Physical dependence • Immobility (bed, chair, or home-bound) • Change in family roles • Loss of work role • Social isolation • Financial dependence • Options limited by protective environment

Sources and notes: The table is from *Disability in America: Toward a National Agenda for Prevention*, Institute of Medicine, National Academy Press (1991), page 79. Note that these IOM categories differ somewhat from those used by the World Health Organization, which uses “disease,” “impairment,” “disability,” and “handicap.” See the above reference p. 76-78 for a discussion of these differences.

Risk Factors and Risk Domains: An important aspect of disability prevention is the treatment of risk factors. Risk factors are characteristics of the person or situation that are causally associated with the diagnostic condition or with the potential for increased degrees of disability resulting from that condition. As seen in Figure 2, risk factors are divided into three domains: biological, environmental (physical and social) and lifestyle and behavioral. For each targeted condition, extended care pathways identify the risk factors and preventive interventions that are known to be most closely associated with progression towards the next stage of disability.

Figure 2: Risk Factors and the Prevention Process



Source: Disability in America: Toward a National Agenda for Prevention, Institute of Medicine, National Academy Press, 1991, page 85.

Table 6 presents examples of risk factors within each of three risk domains, as described by the Institute of Medicine.

Table 6: Examples of Risk Factors in Each Risk Domain

Domain	Examples of Risk Factors
Biological	<ul style="list-style-type: none"> • Genetic factors, such as one disease increasing the risk of another (e.g., diabetes increasing the risk for stroke) • Adverse effects of drugs (e.g., the sedating effects of psychotropic drugs increases the risk of falling)
Environmental (social and physical)	<ul style="list-style-type: none"> • Lack of family support • Death of a spouse • Lack of transportation • Social stigma re: dependence on wheelchair • Exposure to pollutants • Lack of access to adequate health care
Lifestyle and behavioral	<ul style="list-style-type: none"> • Poor eating ability and inadequate diet • Tobacco use, alcohol use, drug use • Stress • Sedentary lifestyle • Inadequate coping behavior

Operationalizing the ECP Concept

Using the principles identified in the health status cycle and the prevention of disability concepts, two steps are needed to support the creation of actual extended care pathways:

- a **format** needs to be developed for writing and sharing the extended care pathway; and
- the **content** of the pathway needs to be identified.

Among NCCC members, the following assumptions guide the development of format and content:

- Pathways are condition-specific. The “condition” could be a diagnosis, set of related diagnoses, or a broader condition, as long as a sufficient level of detail can be included to guide practice behavior.
- Pathways cross settings, covering the transitions and choices among a variety of services or types of care.
- If there are detailed pathways and protocols within any one setting (e.g., protocols for choice of drug therapy), these should be consistent with the overall pathway.

ECP Format:

In building extended care pathways, NCCC members have adapted the format of the critical path, developing grids showing recommended care over time. Categories of the intervention, called standard components, can be used across all settings. These are:

- context;
- assessment;
- intervention;
- roles and responsibilities of helpers (usually implied but can, and sometimes should be, made explicit);
- transfer of information; and
- outcomes.

Table 7 shows the subcategories of the ECP components. Each care setting will probably need only a subset of the categories listed, and should select those that seem most appropriate as the pathway is being written. For some settings, additional categories may be needed to facilitate seamless care for the patient/client who is moving from one setting to the next.

Table 7: Standard Components of Care Pathways

Component	Subcomponents
Context	<ul style="list-style-type: none"> • Setting of care (e.g., home care, acute care) • Specified time scale appropriate to setting (e.g., day 1, week 3) • Goals of care in this setting
Assessment	<ul style="list-style-type: none"> • Physical exam • Physician's history • Tests • Other consults • Nursing assessment • Psychosocial assessment • Psychological and/or psychiatric assessment • Caregiver assessment • Financial assessment • Physical environment assessment
Intervention	<ul style="list-style-type: none"> • Nutrition • Medication • Treatments and procedures • Restorative care/maintenance of function (e.g., PT, OT, ST) • Equipment and supplies • Teaching/counseling • Socialization/recreation • Medical management • Caregiver support • Spiritual support • Prevention • Legal/financial management • Community maintenance (e.g., transportation and housing adaptation) • Continuing care needs
Information Transfer	<ul style="list-style-type: none"> • Content • Method
Outcomes	<ul style="list-style-type: none"> • Points of measurement • Outcomes to measure

Table 8 presents selected categories in chart form, as a basis for developing a setting-specific pathway. The list of components is noted in the far left column. The additional columns would be labeled with units of time. The broadest concept used would be the stages in the Health Status Cycle (asymptomatic, symptomatic, etc.). In various specific settings, the time labels might be day 1, day 2, day 3 for a hospitalization, week 1, week 2, week 3 for a nursing home stay, etc. Using this grid format, the specified interventions for a particular time period can be written and shared.

Table 8: Framework for a Setting-specific Care Pathway

Components	Unit of time	Unit of time	Unit of time	Unit of time
I. Assessment Physical exam Physicians' history Tests Other consults Nursing assessment Psychological/psychiatric assessment Caregiver assessment Financial assessment Physical environment				
II. Intervention Nutrition Medication Treatment/procedures Restorative care/maintenance of function (PT, OT, ST) Equipment and supplies Teaching/counseling Socialization/recreation Medical management Caregiver/counseling supports Prevention Legal/financial management Community maintenance (e.g., transportation, housing adaptation) Spiritual support Continuing care needs				
III. Information Transfer Content Method				
IV. Outcomes Points of measurement Outcomes to measure				

ECP Content: Example—Stroke

The next step in developing an ECP is developing basic content that reflects the conceptual framework. As an example, NCCC members working on extended care pathways developed a pathway for the condition of stroke.

- First, general summary information was prepared regarding the prevalence, natural history (e.g., trajectory of the condition), and financial and personal burden associated with the disease (see Appendix C). This information was gathered from a literature review and the contributions of clinicians from various disciplines.
- Second, for each stage of the health status cycle (e.g., asymptomatic, symptomatic, functional decline, functional recovery, and adjustment), patient goals, risk factors, interventions, and outcomes were established, resulting in a condition summary. Again, the source of this information was the literature and clinicians. Interventions that could eliminate or reduce a client's risk of progressing along the pathology-disability continuum were selected.

Tables 9 through 11 present the risk, care issues, and interventions by health status for stroke identified in steps one and two above.

Next Steps: An Operational Pathway; Example—CVA

The foundational materials developed in the creation of the ECP's basic format and content are then developed into an operational ECP that fits a specific provider system. Table 12 presents a pathway developed for CVA in the rehabilitation setting. The developmental process at the network level is described in Section 3.

Table 9: Risks, Care Issues, and Interventions by Health Status: Stroke Asymptomatic and Symptomatic Stages

Stage	Goals	Risk Factors	Interventions	Outcomes
I. Asymptomatic Before development of pathology	<ul style="list-style-type: none"> • Achieve and maintain general good health and fitness • Prevent hypertension and cardiovascular disease 	<ul style="list-style-type: none"> • Biological <ul style="list-style-type: none"> - genetic - age - gender - race - elevated serum cholesterol • Social/ environmental <ul style="list-style-type: none"> - lack of responsibility for own health - lack of access to regular medical screening • Lifestyle and behavioral <ul style="list-style-type: none"> - sedentary lifestyle - obesity - smoking - non-compliance with regimen to treat diseases posing high risk 	<ul style="list-style-type: none"> • Community <ul style="list-style-type: none"> - general health promotion - educational interventions • Medical care systems <ul style="list-style-type: none"> - focus on physical fitness, healthy diet (e.g., high fiber, low cholesterol) - smoking cessation - special strategies to screen those at higher risk and unlikely to have regular periodic care (e.g., minority males, isolated elderly, those without health insurance) 	<ul style="list-style-type: none"> • Presence of risk factors • General level of health and fitness • Has physician, periodic screening • Morbidity (e.g., presence of hypertension, cardiovascular disease) • Service use • Quality of life
II. Symptomatic Circulatory changes consistent with hypertension and with cardiovascular diseases	<ul style="list-style-type: none"> • Identify conditions early • Treat to lower blood pressure • Treat atrial fibrillation • Lower serum cholesterol • Control co-morbidities (e.g., diabetes) • Prevent stroke 	<ul style="list-style-type: none"> • Biological <ul style="list-style-type: none"> - hypertension (40% of strokes can be attributed to systolic bp of more than 140.) - coronary heart disease (Persons with cardiac impairment have twice the risk of stroke. For MI and atrial fibrillation the risk is much higher .) - previous stroke (Nearly 30% of stroke survivors have another stroke within 10 years. Of TIAs, 35% to 50% go on to have a completed stroke.) • Social/ environmental <ul style="list-style-type: none"> - lack of access to regular medical care • Lifestyle and behavioral <ul style="list-style-type: none"> - noncompliance to the medical regimen and/or lifestyle changes - high-stress lifestyle 	<ul style="list-style-type: none"> • Screening for hypertension and elevated cholesterol <ul style="list-style-type: none"> - annual blood pressure screening in physician's office or ambulatory care - special strategies to screen those at higher risk and unlikely to have regular periodic care (e.g., minority males, isolated elderly, those without health insurance) • Treatment <ul style="list-style-type: none"> - treat hypertension to keep diastolic pressure in the range 85/99 Hg (up to age 80). In a population treated there was 45% reduction in stroke incidence. Treatment might include weight loss, diet to decrease cholesterol and salt intake, smoking cessation, increased physical exercise, and/or medication • Other prevention of stroke <ul style="list-style-type: none"> - diagnosis and treatment of TIAs - identify noncompliance issues and address them directly (e.g., treatment perceived as more uncomfortable than disease, low income, sensory or cognitive impairment, limited knowledge of condition and treatment regimen, problematic access to care, cultural barriers, low social support for compliance, no support for reduction of stress in lifestyle) 	<ul style="list-style-type: none"> • Presence of risk factors • General level of health and fitness <ul style="list-style-type: none"> - functional status - has physician - periodic screening • Receiving treatment • Morbidity, specifically presence of hypertension, cardiovascular disease • Service use • Quality of life

Table 10: Risk, Care Issues and Interventions by Health Status for Stroke Functional Decline and Functional Recovery Stages

Stage	Goals	Risk Factors	Interventions	Outcomes
<p>III. Functional Decline - Stroke</p> <p>The acute phase for stroke is the first 48 hours after occurrence. For a large percentage of stroke victims, immediate admission to an acute care hospital occurs within this time period.</p>	<ul style="list-style-type: none"> • Differential diagnostic: stroke vs. pseudo-stroke (e.g., seizure) • Identify stroke etiology and type • Stabilize vital signs and treat coexisting illnesses • Prevent life-threatening complications: recurrent embolic stroke, deep venous thrombosis, pulmonary embolism, pneumonia, seizures • Determine stroke-related deficits compared to pre-stroke status: cognitive status, affective status, communication, vision and hearing, swallowing, motor control, sensation, perceptual function, postural control • Provide support and education to the family 	<ul style="list-style-type: none"> • Biological <ul style="list-style-type: none"> - co-morbidities - advanced age 	<ul style="list-style-type: none"> • Medical care systems <ul style="list-style-type: none"> - treat co-morbidities 	<ul style="list-style-type: none"> • Functional status • Morbidity, mortality • Risk factors • Discharge disposition • Cost • Service use • Quality of life
<p>IV. Functional Recovery</p> <p>Rehab phase begins after the first 48 hours or at the time of medical and neurological stabilization and extends for three months. Multidisciplinary rehab starts in the acute care hospital and continues in several possible settings depending on patient condition: rehab unit or hospital, extended care, SNF, outpatient, adult day health, and home health care.</p>	<ul style="list-style-type: none"> • Maximize function, including: <ul style="list-style-type: none"> - restore motor and sensory function in affected limbs - train and strengthen unaffected side - improve and train in ADLs, transfer, and ambulating - restore combination skills • prevent complications that may limit recovery • prepare patient and family for return to pre-stroke setting or other appropriate living situation 	<p>Risks for limited restoration</p> <ul style="list-style-type: none"> • Biological <ul style="list-style-type: none"> - complications* - significant co-morbidities - perceptual dysfunction - long interval between CVA and admission to rehab - cognitive impairment • Social environmental <ul style="list-style-type: none"> - caregiver withdrawal, burnout • Lifestyle and behavioral <ul style="list-style-type: none"> - poor adjustment to disability • Risks of discharge not to home <ul style="list-style-type: none"> - biological: limited recovery, recovery very slow, incontinence, cognitive impairment - social/environmental: lives alone, no capable informal caregiver - environmental, physical: physical barriers, lack of safety equipment 	<ul style="list-style-type: none"> • Interventions for limited restoration risk factors <ul style="list-style-type: none"> - prevent or treat immediately during rehab - good medical management program to identify early and treat specifically - begin rehab as soon as possible - give trial of therapy** - counseling, respite, other support, stroke club • Interventions for risk of discharge not to home <ul style="list-style-type: none"> - continue rehab in new setting - treat, train in management - provide care in least restrictive setting - assess home, community-based long-term care - assess and adapt home - provide equipment and training in its use 	<ul style="list-style-type: none"> • Functional status • Risk factors • Discharge disposition • Cost • Morbidity, mortality • Service use • Quality of life

* Complications might include medication toxicity, sensory deprivation syndrome, depression, spasticity, shoulder problems, pressure sores, urinary incontinence, constipation and fecal incontinence, peripheral nerve palsies.

** A two-week trial of therapy is recommended for all patients. A decision on whether to continue therapy is based on ability to comprehend verbal or nonverbal directions, follow 2-3 step commands, and retain learned skills from one day to the next. Criteria for selection of appropriate setting should be established.

Table 11: Risks, Care Issues, and Interventions by Health Status: Stroke Adjustment Phase

Stage	Goals	Risk Factors	Interventions	Outcomes
<p>V. Adjustment Phase</p> <p>The adjustment phase begins after three months and continues indefinitely. During this phase functional condition is stabilized; some functional recovery may occur for two years or more.</p>	<ul style="list-style-type: none"> • Achieve maximal health status • Maintain functional gains • Modify risk factors for recurrent stroke • Adapt to any remaining functional limitations • Prevent disability • Resume social functioning 	<p>Risk factors for further limitation or disability</p> <ul style="list-style-type: none"> • Biological <ul style="list-style-type: none"> - depression - functional declines during hospital stays for acute illness • Social/environmental <ul style="list-style-type: none"> - caregiver burnout - encouraging dependence in client - lack of support to resume social roles • Environmental/physical <ul style="list-style-type: none"> - architectural barriers (home or work) - lack of transportation • Lifestyle and behavioral <ul style="list-style-type: none"> - lack of routine <p>Risk of recurrent stroke</p> <ul style="list-style-type: none"> • Biological <ul style="list-style-type: none"> - cardiac co-morbidity - hypertension - diabetes • Lifestyle and behavior <ul style="list-style-type: none"> - noncompliance with regimen (e.g., low income, sensory and cognitive impairment, limited knowledge of condition, problematic access to care, cultural barriers, low social support for compliance) 	<p>Intervention for risk factors for further limitation or disability</p> <ul style="list-style-type: none"> • Biological factors <ul style="list-style-type: none"> - assess for depression frequently, treat with antidepressants when present - stroke club to encourage adjustment to status - early mobilization, short course of therapy after any hospitalization • Social/ environmental <ul style="list-style-type: none"> - counseling, respite, support group information and support - counseling, intermittent short courses of rehab - specific attention to social functioning • Environmental/physical <ul style="list-style-type: none"> - assess environments - make accessible if possible - vocational rehab if desired - identify source of transportation <p>Interventions for risk of recurrent stroke</p> <ul style="list-style-type: none"> • Biological factors <ul style="list-style-type: none"> - medical management (e.g., diet, weight, no smoking) - reduce blood pressure below 160/90 Hg) • Lifestyle and behavior <ul style="list-style-type: none"> - identify reasons and address them 	<ul style="list-style-type: none"> • Presence of risk factors • General level of health and fitness • Has physician, periodic screening • Morbidity (e.g., presence of hypertension, cardiovascular disease) • Service use • Quality of life

Table 12: Continuing Care Pathway — CVA

The following sample pathway is one of many developed by Lutheran General HealthSystem in Park Ridge, Illinois.

Section 3: Implementing Extended Care Pathways in a Chronic Care Network

As networks develop the conceptual framework for ECPs, they have to simultaneously think about how ECPs will be implemented in their local networks. The major questions confronting them, and addressed in this section, are:

- What will an ECP look like in operation?
- How do we go about planning and developing ECPs?
- How should we implement ECPs so that they are really used?
- Once ECPs are operational, how will we determine what effect they are having?
- Is the ECP approach feasible?

All of these questions ultimately have to be answered locally, but some general directions have been gleaned from the experience of NCCC members involved in previous change efforts, especially the development of acute care critical paths. This section also relies on information found in *Health Outcomes Institute* (1993), *Henry Ford Health System* (1993), *Hospital Case Management* (1993), *Geehr* (1992), and *Schwartz and Cohen* (1993).

What An Extended Care Pathway Looks Like in Operation

NCCC members working on ECPs have developed the following vision to guide them in planning how ECPs will operate within their chronic care networks:

- Within the network, care providers will decide jointly upon the most appropriate care for the entire natural history of a particular condition.
- The network will develop the organization and capacity to provide the necessary care. This will include information/communication systems and funding to support the provision of the prescribed care in all the appropriate settings.
- The providers will all operate as members of the same team. The ECP will be identified as appropriate for the patient/client by condition, wherever he/she enters the system.
- The patient/client receiving care for the particular condition will know what to expect, will participate in the care process, and will experience the care as seamless, including all transitions between settings, levels of care, and providers.
- Care decisions will be grounded in state-of-the-art knowledge and based on what is best for the patient/client, not driven by finances or by issues of turf or disciplinary bias.

Planning and Developing Extended Care Pathways

In developing ECPs, NCCC members have found it useful to establish an ECP oversight committee and focus on key areas in the planning process. They have also learned practical lessons “from the field.” These activities are described as follows.

Establishing an Oversight Committee

Because the vision described above represents a major culture change within a health care system, the NCCC recommends the establishment of a network-wide interdisciplinary steering or oversight committee charged with the following responsibilities:

- articulate the goals;
- plan the pathway development effort;
- assign responsibility for all parts of the tasks;
- identify resources to be used in the development and implementation effort;
- get all parts of the organizations to work together; and
- develop network-wide support for implementation of the pathways.

Areas of Focus

NCCC experience suggests that it is most helpful to focus the planning process on the following six activities.

Criteria for selecting targeted conditions. For example, what will be the scope of the pathways? Will pathways be the new way of doing business for all (or almost all) patients/clients, or will the program remain focused on a limited number of target conditions?

The development process. Committees with participants from all the disciplines and settings will be needed for pathway development. A different committee will probably be needed for each pathway. Information-gathering activities may include conducting a literature review, making site visits to places with operational pathways, working with consultants, and collecting all relevant guidelines and care plans currently in use within the system or available from professional associations.

The relationship of extended care pathways to existing related functions. For example, the network will consider how ECPs relate to the network's: communication procedures, medical records, information systems, and utilization review procedures.

Gaining widespread support for implementation. Starting from the time the network first commits to the project, the administration needs to cultivate support throughout the entire network. Strategies for fostering support include expanding support downward from top management and developing a rationale for change that is understandable and compelling to all members of the system.

The implementation process, including: a pilot test of one pathway before modifying the documentation, forms, communications, etc., affected by the pathway; training for all care providers in the use of pathways; and a process to keep pathways up to date with future changes in health care knowledge and practices.

The review/quality improvement/evaluation process for the pathways.

Eight Lessons from the Field

Change is difficult for both people and organizations. From NCCC experience with ECPs, several important lessons have emerged.

From the start, mobilize support for change from the top.

This support must continue throughout the ECP effort, moving down through the organization as the program develops. Champions, leaders, and department heads will not actually be using the

pathways day-to-day, and their acceptance and support will not automatically “trickle down” to the care providers at the patient/client level. In addition, special efforts will be needed to gain physician support, as experience suggests that physicians are the most difficult to enlist.

Use multidisciplinary teams in the development of all pathways.

Involving multidisciplinary teams will ensure that better pathways are developed, and will facilitate buy-in from all disciplines. No one discipline should be seen as dominating the initiative. The multidisciplinary approach is the best way to plan for transitions and help providers understand the perspectives and burdens of their colleagues. This shared development process actually increases coordination across settings even before pathways are implemented.

Choose the initial condition carefully.

NCCC members recommend beginning with a relatively simple condition or possibly a surgical procedure. In any event, the condition should be amenable to raising real concerns, such as acute length of stay, variability in practice patterns, or unsatisfactory transitions between settings. It is helpful if the first condition can serve as a model for other pathways; thus, atypical or especially complex conditions may not be a good choice.

Ensure that the pathway documentation is part of the patient/client medical record from the beginning.

The pathway shouldn't be an add-on, or it is likely to be buried by competing day-to-day pressures. In most organizations the patient/client record has grown by accretion and contains many redundancies; it should be thoroughly reviewed with an eye to streamlining and computerization.

Don't underestimate the amount of time and effort required and the cultural change that is being initiated.

Administration must create the support needed for implementation and remove barriers as they are identified. For maximum effectiveness the pathways should be written by care providers while additional staff complete the administrative work necessary to keep the effort moving forward. The use of consultants can also facilitate ECP efforts.

Pilot test the initial pathway before involving many people in developing many pathways.

ECPs represent a new field of research and practice. NCCC members recommend that ECP committees remain flexible to new ideas throughout ECP development, and test new pathways on a small scale before moving on to larger, more intense efforts.

The hospital part is actually the easiest, but don't let it dominate the process.

Most pathway experience to date has been in developing acute care critical paths; there is a tendency to see pathways as starting (and perhaps ending) in the hospital. However, NCCC members have often found success in starting pathways in primary care physician practice, where most patients/clients enter the health care system, and include care in all settings appropriate for a particular condition. Content and format need to be tested for relevance and applicability in all settings.

Plan for automation as pathways are developed.

A major obstacle to the development of extended care pathways is the lack of a mechanism for collecting and sharing clinical information across all sites of care. Even within one site, integrating

information across all disciplines can be complex. Pathway development should be accompanied by planning for automation. For extended care pathways to be most successful, it will probably be necessary for all sites of care to have ready access to the shared patient/client record.

Implementing Extended Care Pathways

Successful implementation of extended care pathways requires careful attention to at least these five areas:

- train those who will provide care under pathways;
- promote new behaviors;
- change the environment;
- provide ongoing support; and
- address the regulation and reimbursement issues of delivering care.

Train Providers

Care providers who will be expected to use the pathways will have to be trained in their use. Designing, scheduling, and systematically conducting the needed training will probably require the assistance of training specialists as well as administrative support.

Involving the care providers who participated in development or in the pilot test will help spread the excitement to those just becoming involved.

Trainees will demand evidence that the need for such a change is compelling. The fact that leaders believe the need exists will not, in itself, be convincing. Whenever possible, training groups should include providers who work together across sites, so that contacts can be initiated and relationships begun.

Promote New Behaviors

Putting the newly developed extended care pathways into everyday use requires new behaviors on the part of all providers. The aim is not simply use of pathways in particular situations, but rather, consistent use across multiple disciplines and care settings. Clearly, providing the forms and initial training will not be enough.

In a recent article on changing physician behavior, Schwartz and Cohen supply an attractive framework for addressing that part of the implementation equation that is the behavior of individuals. The model is generally applicable to health care providers. The Schwartz and Cohen model, depicted in Figure 3, indicates that there are many factors influencing behavior change. A premise of the model is that instead of trying to change a person directly, change can be effected by altering the factors that influence a person's judgment, decision-making process, and actions. These factors are the information process, motivation, and changes in the environment.

Figure 3: Model of factors influencing behavioral changes

Knowledge	Cues
Judgment	Information process
Decisions	Motivation
Actions	Environment

From J. Sanford Schwartz, M.D., and Stuart J. Cohen, "Changing Physician Behavior" in *Primary Care Research: An Agenda for the 90s*. U.S. Department of Health & Human Services (September 1990): p. 46.

The model's creators describe behavior change in this way:

Behavior is a complex phenomenon. Actions are precipitated by stimuli or *cues*. These cues are integrated with existing *knowledge* through a complex series of cognitive steps referred to as *information processing*. The result is a *judgment*. In the presence of sufficient *motivating factors*, these judgments are transformed into *decisions* (intention to act). When the *environment* is sufficiently supportive, decisions are transformed into *actions*.

According to this model, behavior change might be facilitated by improving knowledge, strengthening cues and stimuli, optimizing information processing, altering motivations, or *modifying environment*.

This points to the importance of factors beyond training, and in fact, allows a shift of emphasis to the environment in which pathways will be implemented.

Change the Environment

Many administrative and organizational factors can change the environment. For example:

- Identify and remove institutional barriers to the use of pathways.
- Build support systems for the desired behavior (e.g., improve forms and procedures, expand computer capabilities to include pathways).
- Reinforce behaviors when they occur by using pathways as the basis for feedback mechanisms and reporting requirements.
- Design appropriate incentives for compliance and ensure regulations are in line with desired behaviors.

Evidence suggests that efforts to change behavior are most likely to be successful when interventions occur on several fronts. The broad brush approach spreads the burden of change over many individuals at all levels within the network, ensuring that providers don't bear the full weight of implementation.

Provide Ongoing Program Support

Once a pathway effort is underway, several processes are needed to sustain the effort:

- continuous reporting to the program designers and overseers during implementation so that key issues can be resolved as they arise. Eventually a permanent oversight structure or process will be assigned responsibility for the established program.
- synchronicity of pathway development, the development of a clinical and financial computerized database, and planning for evaluation.
- continuous training in pathway use for all providers involved (and for new providers as they join the network).
- familiarity with emerging professional guidelines and health care practices. ECP revisions should be considered by the same broad-based interdisciplinary committee that originally developed the pathway.

Address the Regulation and Reimbursement Issues of Delivering Care

Extended care pathways are not supported by current regulation or reimbursement of patient/client care. In fact, many regulations work at cross purposes with the goal of integration. Some legislation even prohibits forms of coordination among organizations. Similarly, fragmented reimbursement for care discourages viewing the care continuum as a whole and sharing responsibility (and risk) for the scope of care.

NCCC members who have pursued care continuity through extended care pathways have had to negotiate exceptions and waivers to regulations and work with or obtain more flexible sources of funds, such as HMOs, grants, and private foundations. They have had to negotiate unusual arrangements with care-providing partner organizations.

Determining the Effects of Extended Care Pathways

The NCCC believes that ECPs will improve care for people with chronic conditions. How can we demonstrate whether this is true? In determining the effect of ECPs, it is useful to assess:

- Levels of evaluation
- An outcomes framework
- Implementation milestones
- System-wide outcome measures

Levels of Evaluation

Several levels of evaluation are required in the development and implementation of ECPs. For example:

- determine whether selected milestones are being reached as planned and in a timely fashion.
- identify whether ECPs are operating as planned. (For example, has the care system actually changed to incorporate the ECPs? Are the inputs, process, and outputs as expected?)
- improve quality of care over time. The ECP represents a standardized process, and CQI will be used by some sites to improve the process over time.

- identify impact of ECPs on outcomes of interest. Now that ECPs are operational, what is the result for patients/clients, providers, organizations and the whole system? This requires collecting data over time, making comparisons with some “before” measures, assessing system performance, determining consistency of measures across settings, and adopting a patient/client focus.
- evaluate ECP effectiveness compared to the regular system. Answering this question with surety would require a research study with a sufficient sample size for the analysis techniques used and probably randomization or a comparison group. Such studies should be used to compare acceptable and effective methods of intervention. This shouldn’t be done until it has been established that the ECPs are operational and having a desirable impact.
- prove efficiency. Efficiency is an interaction between effectiveness and cost (looking for the most effective intervention for the least cost). The question of cost is very important and will be looked at in every stage of review. It is only when interventions of known effectiveness can be compared on cost that the most efficient intervention can be selected.

Note that the first four tasks are conducted within a health system as a regular part of doing business. The last two bullets describe tasks typically done by outside evaluators for a small number of programs.

An Outcomes Framework

A critical component of the evaluation process is establishing an outcomes framework. NCCC members working on ECP development have found the following framework to be effective when considering outcomes:

- The ECP effort is divided into two stages:
 - Stage one includes ECP design, development, and implementation
 - Stage two represents the standard way of doing business
- Within each stage, two areas are selected for examination:
 - the care process (i.e., inputs, process, and outputs)
 - outcomes (some of which might be considered intermediate)
- Four distinct audiences are identified for the outcomes of interest:
 - the patient/client;
 - the single setting including the individual clinical provider;
 - the system or network; and
 - the population.

Tables 13 and 14 depict the desired outcomes organized within this structural framework, for stages one and two.

**Table 13: Outcomes for Extended Care Pathways in Stage One —
Design, Development and Implementation**

Stage/ phase	Client Outcomes	Single Setting/Clinical Provider Outcomes	System/Network Outcomes	Population Outcomes
<p>Stage 1: A. Process (i.e., input-process-output)</p>		<ul style="list-style-type: none"> • All disciplines had input • Participants learned about pathways • All use the same glossary • Includes all standard components compatible with NCCC • Pathways identify when a person changes health status • They deal with transitions between levels of care and settings • Pathways are flexible enough to use with persons with multiple chronic conditions • Care decisions on pathways are patient-centered, not driven solely by finances • Development process exists and is documented 	<ul style="list-style-type: none"> • Responsibility assigned and resources allocated to proceed to implementation • Conditions selected based on criteria developed • All sites of care slated to use pathway were involved in development • Established relationships between care settings included in pathway • Mechanism exists for cooperative planning between settings • Caregivers in different settings feel they are part of the same team • Pathways are consistent with regulations governing all settings 	
<p>Stage 1: B. Outcomes</p>		<ul style="list-style-type: none"> • Extended care pathways are implemented • Pathways incorporate national standards 	<ul style="list-style-type: none"> • Pathways supported by policies, education/ training of clinicians, documentation/ information system 	

Table 14: Outcomes for Extended Care Pathways in Stage Two — Operating Pathways

Client Outcomes	Single Setting/Clinical Provider Outcomes	System/Network Outcomes	Population Outcomes
<p>Stage 2: A. Process</p> <ul style="list-style-type: none"> • Client sees care as more continuous • Client knows what to expect • Decreased movement between settings 	<ul style="list-style-type: none"> • Simpler process • ECP being used in daily practice • Established procedures are used regularly • Someone is responsible/accountable across settings • Everyone on team always knows who is currently responsible • Clinicians plan with longer time horizon • Providers see care as a continuous process • Increased awareness of care being provided by others • Team members have more information on client than they used to • Improved documentation of care 	<ul style="list-style-type: none"> • Less duplication • Increased responsibility and accountability for care across settings • Improved prevention services • Senior managers aware of pathways and use new language • Care language is more person-centered and multi-environmental • Increased communication among providers • Increased collaboration around transitions 	
<p>Stage 2 B. Outcomes</p> <ul style="list-style-type: none"> • Improved management of chronic conditions (disease-specific outcomes of care*) • Decreased acute episodes of chronic conditions* • Decreased unplanned hospital, nursing home admissions • Decreased readmissions and at decreased acuity level • Increased prevention behaviors • Decreased drug interactions • Decreased morbidity • Decreased progression to disability • Decreased unmet needs due to co-morbidity • Increased sense of control of health • Increased consumer knowledge and self-care • Increased consumer and family satisfaction with care • Decreased anxiety over health • Decreased caregiver burden • More time spent in settings of choice • Increased quality of life 	<ul style="list-style-type: none"> • Clinical outcomes specific to managing care within one setting • Increased efficiencies within settings • Fewer missed appointments • Fewer phone calls at off hours • Less decision making with an incomplete database • Fewer episodes or amounts of expensive care (intensive care, ER, terminal care, long stays) • Increased job satisfaction for providers 	<ul style="list-style-type: none"> • More efficient use of resources (percent of system expenses for administration)* • Decreased time making transition between settings • Decreased inappropriate service or provider use • Decreased redundancy of service per episode* • Improved quality of care; hospital readmissions* • Episode prevention; decreased hospital admissions per member per year* • Decreased voluntary disenrollment from managed care • Decreased employee turnover • Increased member satisfaction* • Decreased illness-based medical care episodes per member per year* • Improved financial performance: profitability, debt service coverage ratios* 	<ul style="list-style-type: none"> • Improved health status of population* • Improved prevention index of population*

* CRISP indicator of system effectiveness. For more on the CRISP project, see Henry Ford Health System, 1993.

Clearly no one site will choose to measure all these outcomes. Members will choose those parts most relevant for them. Also note that the items listed in Table 14 are characteristics that would be indicators, not actual measures; NCCC members feel that some of the indicators would be very difficult to measure.

Implementation Milestones

During the NCCC committee's work on ECPs, NCCC members developed a survey to identify member progress in designing, developing, and implementing ECPs. Survey questions represented milestones in the ECP effort and were derived from the indicators listed in the framework. The questions are shown in Table 15.

System-wide Outcomes Measures

The challenge to measuring the outcomes of operational pathways (Stage Two) comes from the very characteristic that the NCCC is trying to promote with ECPs — seamlessness. Most providers are accustomed to measuring some outcomes as patients are discharged from their setting. Measures of the effectiveness of a seamless intervention must include and transcend all settings, i.e., be network-wide or population-based. Some indicators must be measured the same way across all settings. Continuity has to be maintained by making the measurement patient/client-focused. This information must then be collected, maintained, analyzed, and shared throughout the network.

Identifying measures of system effectiveness has been undertaken by the Center for Health System Studies of the Henry Ford Health System in Detroit (see *Henry Ford Health System*, 1993). Their Consortium Research on Indicators of System Performance (CRISP) is developing, testing, and implementing a health care system performance measurement program. CRISP performance indicators are identified in our outcomes structure (Table 14) with an asterisk.

Feasibility of the Extended Care Pathways Approach

The descriptions in Section 4 illustrate how two specific networks established extended care pathways at their sites. Within the same conceptual framework, these two networks started from different perspectives (CQI and patient-focused care), followed somewhat different courses, and developed somewhat different ECPs for the same condition: stroke. Other NCCC member networks have been moving forward with this process as well. NCCC work to date strongly suggests that this approach is on the right track and will make important improvements in integrating chronic care services, with resulting desired changes in the cost, quality, and continuity of care.

Table 15: Implementation Milestones from the NCCC's ECP Survey

<p>Has a person been assigned responsibility for leading the ECP development and implementation? Have resources been identified (person hours, \$)? Has a process been outlined for developing ECPs? Have conditions (diagnoses) been selected? Has effort been focused on a particular discipline? Which one? Are there working relationships between and among all the settings included in the pathways...</p> <ul style="list-style-type: none">• at the organization level?• at the clinical (pathway) level? <p>Which diagnoses have been selected for ECP development? Have committees been formed to develop the ECPs? What care settings/ types will be incorporated into the pathways...</p> <ul style="list-style-type: none">• primary care — MD office or clinic?• acute care?• rehabilitation?• transitional care?• skilled care in a nursing home?• long-term nursing home care?• home health care?• community-based long term care?• adult day (health) care? <p>Does each committee include representation from all settings necessary for the pathway? Does each committee include representation from all the disciplines necessary for the pathway? Have any of the pathways been developed (written)? If Yes.... Do the pathways all have a standard format? Do they include all NCCC standard components? (See list at end of previous chapter.) Are they consistent with regulations governing the settings included? Do they incorporate national standards (where these exist)? Do they cover transitions...</p> <ul style="list-style-type: none">• between levels of care?• between settings? <p>Do they cover changes in health status? (Is this the same as changes in level of care?) Do they cover changes in psychosocial needs? Do they cover health promotion and preventive care? Are the care decisions in the pathway patient-centered rather than driven by reimbursement? Are they flexible enough to be used for patients with multiple conditions?</p> <p>Is the use of the pathways supported by/ required by organizational and health system policy? Has a plan been developed for implementation of the pathways? Has any pilot testing of the pathways taken place? Are pathways incorporated into the patient/client record? Have clinicians been trained in the use of the pathways? Are client records shared across all settings in a pathway? Across some settings? Are client care plans shared across all settings in a pathway? Across some settings? Is there a clinical computerized database accessible across all settings in a pathway? Across some settings? Are pathways or their documentation part of the information system? Is there a system in place for measuring the outcomes of pathways? Are reports being developed describing the effectiveness of their use? Is there a system planned to monitor their functioning and make changes in the process as necessary? Is this system in place? Are any of the pathways in regular use? In which settings...</p> <ul style="list-style-type: none">• primary care — MD office or clinic?• acute care?• rehabilitation?• transitional care?• skilled care in a nursing home?• long-term nursing home care?• home health care?• community-based long term care?• adult day care? <p>Does documentation of the development process exist?</p>

Section 4: Case Studies of Extended Care Pathways in Two Chronic Care Networks

Approximately half of the NCCC's 24 sites are in the process of establishing extended care pathways. This section provides important information from two sites — Lutheran General HealthSystem in Illinois and St. Mary Medical Center in California — that are implementing pathways for several conditions. Their stories highlight many of the advantages and potential pitfalls associated with ECP development and implementation.

Lutheran General HealthSystem

Located in the Chicagoland area, Lutheran General HealthSystem is a founding member of the NCCC and has been a national leader in developing integrated chronic care services. This case study includes information about:

- Background and the Need for Pathway Development
- Using the FOCUS CQI Method as a Starting Point
- From Common Protocols to Continuing Care Pathway
- The Design Phase
- Implementation Path

Background and the Need for Pathway Development

About Lutheran General HealthSystem

In 1995 Lutheran General HealthSystem (LGHS), merged with Evangelical Health System to form Advocate Health Care. In 1994 when this report was primarily written, LGHS was a network of health and human service organizations offering a full array of valuable services.

Although the quality of services was excellent, several problems with service delivery in the 1980's led LGHS to consider the development of ECPs. The greatest problem was lack of service integration. Until recently, services geared toward the elderly were located in several subsidiary corporations. They had evolved as very separate, and sometimes competitive, entities with their own culture, priorities, and goals. Callers needing specific information or services were frequently transferred from department to department even though a central number for information about elderly services has been operational for ten years. An assertive caregiver or well older person may have been able to locate appropriate services, but the older or more frail person may have found it difficult or impossible to obtain needed assistance.

Lutheran General Hospital was also faced with the same problems as most hospitals in the 1980's — shrinking reimbursement from Medicare, shortened lengths of stay, and concerns that patients were being discharged too quickly. Both the hospital staff and nursing homes complained of poor communication between their facilities. It was clear the hospital needed to strengthen its link to community-based services, home care, and nursing homes, and to provide more comprehensive care to older adults while they were hospitalized.

Examination of the problem

In 1989 a committee of hospital administrators, physicians and one administrative representative from OAS was convened to examine these problems. The goal was to better manage frail older adults while hospitalized and improve the integration of care with providers in the community. The end result was a successful interdisciplinary case management model which was implemented on the medical geriatric unit in May 1990. Use of this model generated improved clinical and financial outcomes for the unit. It was soon expanded to other areas in the hospital (orthopedic, gero-psychiatry, neuro-medical).

Protocol development

While the hospital was busy expanding case management, the OAS administrator became involved in the National Chronic Care Consortium. The goal of the Consortium, to integrate acute and long-term care, was still an issue that had not been adequately addressed in Lutheran General HealthSystem. The NCCC stressed the need to integrate case management programs across a continuum instead of having a separate case management program for each site. One of the key ingredients to integrated case management was to develop "common protocols" that enable network providers collectively to prevent, delay, or reduce the ongoing effects of disability throughout a condition's natural progression.

In September 1991, the OAS administrator convened a committee led by the geriatric case manager to examine the development of common protocols as a tool to manage geriatric clients across a continuum. Also during this time, the Common Protocols Committee decided to apply the principles of CQI to case management.

Using the FOCUS CQI Method as a Starting Point

"FOCUS," a continuous quality improvement method for organizing process improvement efforts, provided LGHS with a starting point for ECP development. Its letters stand for these components:

- F: Find the problem
- O: Organize the efforts
- C: Clarify knowledge
- U: Understand process capabilities
- S: Select a strategy

At the time that this document was being written, F, O, and C had been applied to LGHS's ECP effort. A key aspect of "C," clarifying knowledge, is to develop the pathways. Analyzing and improving pathways, associated with the "U" and "S" in the FOCUS model, will occur after ECPs have been developed. Steps F, O and C are described below as they relate to LGHS's effort. The general FOCUS process is depicted in Appendix D.

"F" — Finding the problem

As described in the previous pages, the major problem was that case management programs were poorly integrated across the LGHS network.

"O" — Organizing the effort

The original Protocol Committee realized it should have representation from all the different provider sites. The committee invited clinicians from the different sites and disciplines to join the committee (e.g., nurses, social workers, physicians and therapists).

LGHS is frequently asked, “ How did you choose the sites for the network?” and “Did these sites need to be owned by LGHS?” It never occurred to the committee leaders to work only with sites that the system owned. Too many other sites provided care to common clientele and were essential to an integrated system of care across time and place. At the same time, the committee leaders knew they could not work with all the community providers (e.g., all nursing homes within the service area). The leaders therefore chose to work with **interested** providers who served a large base of the clientele. Outside LGHS this consisted of two nearby nursing homes and the preferred provider home care agency. Within LGHS the following services and providers were chosen: acute care areas with a large percentage of older adults (medical services, rehabilitation, orthopedics, gero-psychiatry), the community-based OAS programs, and interested physician groups from geriatrics, internal medicine, family practice, neurology, orthopedics, rehabilitation, and gero-psychiatry.

Many physicians found it difficult to attend every meeting so they became consultants to the committee, reviewing the developing pathways and the minutes. At least one physician was involved with each small working group. This was very important when developing a tool to guide physician practice. Nurses from the physicians’ offices were also key, as they understood the process at the offices and had easy access to the physicians for input.

“C” — Clarifying current knowledge

Limited communication made it difficult to clarify the current means of managing care **across** multiple sites in the system. Clinicians managed care in their own sites and then sent the patient to the next site with minimal information and communication. Each site used its own assessment and care plan tools. None of these tools was passed on to the next site, so each site re-did the same assessment and developed a new plan of care.

The committee agreed there was not a standardized process in place to manage clients continuously across multiple sites. As such, the goal of the committee became, “develop and implement common protocols that apply to all levels of care and professional domains in responding to the needs of individuals with chronic disabilities.”

From Common Protocols to Continuing Care Pathway

Early experience with protocols and pathways

Prior to the common protocol effort, Lutheran General Hospital had used critical pathways with only limited success in standardizing care in some of the case management areas. The geriatric unit, in fact, had almost no success using critical pathways. The department of medicine did not support their use and the nurses found them limiting in caring for very frail older adults. Hospital nurses were also required to complete a separate care plan, making the pathways an added piece of work. However, with a move toward standardization of medicine and more openness on the part of the physicians, the time seemed right to re-explore these tools. Conceptually, pathways not only seemed to make sense as a tool to manage and standardize care in acute care but also across multiple sites. It did not seem necessary to create a whole new tool (common protocol) if the critical pathway could be adapted to work across the continuum.

While this conclusion seemed obvious to the acute care clinicians, it was not obvious to the community-based, nursing home, and home care clinicians who were not familiar with critical pathways. Education about critical pathways was required before the committee was ready to move in this direction. It also took the acute care clinicians time to understand that the pathways had to be more focused on the functional, rehabilitation, psychosocial, and continuing care needs of the client rather than just on medical treatment.

Committee decides upon a consistent format

During these first few meetings, it became clear that terminology was a large barrier between the sites. The committee was able to agree on a consistent format and standard terminology for all the pathways. The committee chose to call the protocols “Continuing Care Pathways” to describe the ongoing nature of the tools yet still relate them to the critical pathways in the hospital. The committee then chose the diagnoses of stroke, dementia, and depression and divided into three working groups to begin developing the pathways.

Working with the NCCC

Soon after LGHS had reached this point, NCCC’s Care Management Resource Group met to further define common protocols. Clearly, most of the national sites that began the common protocol development had come to the same conclusion: that the critical pathway was a logical format for the “common protocol.” The NCCC resource group also felt the need to emphasize the functional, rehabilitation and psychosocial components of these tools and to develop them based on conditions (diagnoses). This group chose to call these tools extended care pathways and encouraged the sites to develop formats and terminology to meet their individual needs.

Description of continuing care pathways

Because LGHS invited community-based providers into the development process from the beginning, its continuing care pathways (CCPs) are very different from the typical critical pathway. Continuing care pathways are longer and have more detail than critical paths, especially in areas such as function, therapies, continuing care (discharge planning) and psychosocial needs. CCPs are also not as specific and directive as critical pathways since chronically ill older adults do not fall easily into treatment categories.

The Design Phase

Different styles of the working groups

The three diagnosis-based working groups for the pathways on strokes, dementia and depression worked at very different speeds and with different styles (see Table 16). A key source of their success was that one person served on all three subgroups. This person kept the groups informed on progress and pitfalls of other groups and insured consistent terminology on the three sets of pathways. Eventually the groups were able to develop a “generic” pathway for geriatric clients in any setting that covered the standard interventions. The committee’s guiding principle was to keep the pathways clear, simple, and user-friendly, and not to get slowed down on unimportant details.

Development of a fourth pathway

As LGHS embarked on developing the fourth set of pathways (hip and knee replacements) it was clear the committee had developed an effective approach. The time for development had been shortened from eighteen months for the original three diagnoses to four months for hip and knee replacements.

By this time the committee better understood the importance of having a certain amount of resources committed to this task. Even finding someone to type the pathways became an issue, not to mention having a dedicated group of clinicians.

The orthopedic subgroup realized how inappropriate it was to develop an acute care pathway for a chronic care condition without the community providers at the table. The committee now realized that acute care providers make many assumptions about post-hospital care that are not always accurate.

With this deficiency in mind, the orthopedic group rewrote the acute care pathway after input from nursing homes, the rehabilitation unit, and home care providers.

Table 16: Different Styles of Different Workgroups at LGHS

<ul style="list-style-type: none">• The stroke group <p>The stroke group started with acute care and worked its way through the typical progression of a stroke client across the continuum of care. Since this group finished first, much of the terminology it used was integrated into the other groups. The stroke group was also the first to realize the need for the physician's office pathway. The larger committee had overlooked this site despite the increasing evidence that health care reform was focusing on the physicians' practice. The physician participants agreed there was a need to standardize care in the office. The office nurses felt a need to focus the physicians on the other important aspects of chronic care: the psychosocial and continuing care needs.</p> <ul style="list-style-type: none">• The depression group <p>The inpatient gero-psychiatric unit had developed and implemented a critical pathway for depression the previous year. The depression work group used this pathway as a guide while working through the continuum. The group had strong leadership from all the sites, including a gero-psychiatrist, a home care psychiatric nurse and a gero-psychiatric social worker from adult day care. The only disagreement was whether primary care providers could and/or should treat depression. To resolve this dilemma, the group developed an algorithm (flow chart) for the primary care physician's office for the appropriate diagnosis of depression. This chart indicates when a client should have inpatient treatment and when he or she should be referred to a psychiatrist.</p> <ul style="list-style-type: none">• The dementia group <p>It was no surprise that the dementia subgroup had the most difficult time. The original committee questioned the ability to standardize care for dementia clients. The geriatricians, however, wanted guidelines for a condition that was often poorly understood and managed. After much discussion as to where to begin, it became clear that an algorithm was needed to establish a correct diagnosis. The dementia pathway also reminds clinicians to assess for depression and follow the algorithm for depression when indicated.</p> <p>Like depression, dementia is treated in many different sites, so the group covered all areas of the care continuum with no particular order in mind. Since clients are not normally admitted to the hospital with chronic dementia as their primary diagnosis, no acute care pathway was necessary. The group was not interested in acute mental status change since that was not the focus. Many clients with chronic dementia are admitted to the hospital with other acute diagnoses, and clinicians have difficulty managing these clients. Therefore, the group chose to develop a dementia pathway for a client in acute care admitted with another diagnosis.</p> <p>The dementia subgroup decided it could not include all the guidelines to managing clients with dementia in one pathway. Therefore, they decided to use separate guidelines for managing behavioral problems, incontinence, eating concerns, skin care, and falls, and then refer to them in all the dementia pathways. Many of these guidelines were already being used in the hospital but only in certain areas (geriatrics, rehabilitation). The other subgroups chose to refer to these guidelines in the depression and stroke pathways when appropriate.</p> <p>The dementia subgroup also decided to use the pathways to address family education more consistently across the sites. In the past, sites had used different educational material for the clients and the families to teach the same thing. Families often received three booklets on dementia from three different sites, or sometimes received no written material. The dementia subgroup chose material that was appropriate in all types of sites and was inexpensive to purchase. This material is referenced on the pathways under "teaching" to remind clinicians to use it. The other two subgroups realized the benefit of this strategy and selected consistent teaching material for stroke and depression.</p>
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Lessons learned in the design phase

Overall, LGHS learned many important lessons in the design phase of ECP development. These lessons include the following:

- Develop chronic care pathways with all sites participating. The development process of working in teams across sites improves communication and collaboration between the sites.
- Use pathways to improve consistency of care across sites whenever possible.

- Use the last column of a pathway to address transitions and the need for continuity with the new site. Each pathway should be an extension of the next.
- Refer to other pathways and algorithms when appropriate on newly developed pathways.
- Refer to specific protocols and other tools when appropriate. Do not expect the pathways to be all-encompassing.
- Keep the pathways simple, user-friendly and consistent.
- Acquire adequate resources for the project, including committee leadership and secretarial support.

Implementation of Pathways

When LGHS decided to implement ECPs, the "PDSA" CQI method was used as a guide (Appendix D). PDSA stands for: Plan, Do, Study and Act. At the time of the case study, the "Plan" and "Do" components were completed. Steps in completing these processes are described below.

Development of an implementation committee

In March 1993, as the three subgroups were winding down, the committee leaders formed an implementation committee. Using CQI techniques, the implementation group developed a fishbone diagram that covered critical success factors for implementation. The success factors fell into six categories:

- education and communication;
- sponsorship and resources;
- documentation and evaluation of the process;
- client and family involvement;
- accountability; and
- transitions.

Plans were developed to address each of these areas. One of the key decisions from these plans included writing a grant to obtain more resources. The grant requested funding for 2.5 FTEs (two project managers and a half-time project director) to provide education at the sites, oversee the process, and collect data. The committee projected implementing ECPs in eleven sites: five units in the hospital, two nursing homes, home care, two physician offices, and OAS.

Appointment of care coordinator

The committee agreed each site needed to appoint someone to use the continuing care pathways and to be the key contact person for the project managers. The committee agreed that a variety of professionals (nurse, social worker, physician, therapists) could serve, but that an aide, LPN or physician assistant would not be appropriate. This was a dilemma for the physicians' offices since these offices are primarily staffed by LPNs and PAs (physician assistants). Physicians agreed they did not have the time to be primary care coordinators in their offices. It was decided that the two project managers would coordinate care in the physicians' offices in collaboration with the physicians.

Focus on transitions, key data set and communications

The committee focused on transitions between sites since this was where many problems occurred. To assist with this process, the committee flow-charted three clients as they would transition from site to site using the pathways. During this exercise the committee realized a key piece of the process was missing: clients could not be managed appropriately with the pathways if clinicians did not obtain correct information from site to site. The committee developed a list of key ingredients for a common data set and common assessment tool. The implementation committee also developed a communication tool to provide brief notes to the physician about areas of concern to focus on during an office visit.

Relationship of the pathway to the care plan

The committee decided to use the pathway as the actual care plan. To make the care plan individualized for each patient, the hospital used the back of the pathway form as an area to list individual needs, interventions and necessary adjustments in the pathway. The sites agreed to pilot this system as part of their care, and most agreed the pathways were a far superior tool. However, they were not ready to relinquish their old care plan in fear that the new system would not meet Medicare, JCAHCO, or other regulations. The two project managers agreed to help the sites review their regulations and develop guidelines to fit the pathways into their current system. The committee advocated sending a copy of the previous pathways to the next site to document what had previously occurred, e.g., how the client deviated from the plan, what intervention worked, and any individual needs.

Education programs and other items

The implementation committee developed objectives and agendas for two education programs. One was an intensive mandatory workshop for care coordinators and the other a less intensive program for the rest of the interdisciplinary teams. Other items the implementation committee tackled were client consent forms, timeline of implementation tasks, job description and qualifications of project managers, roles and responsibilities of site care coordinators, criteria for client selection, and transporting client records from site to site.

Research committee

The goal of the research committee was to assist with the evaluation of projects implemented by the local NCCC initiative. The committee was comprised of researchers, clinicians, and physicians from the system. While the pathway project leaders were tempted to measure specific client outcomes (e.g., functional status, patient satisfaction) to evaluate the project's effectiveness, researchers stressed the need to evaluate how well the new tools were being used before measuring outcomes. They agreed that the first year's focus should be documenting and evaluating the implementation process, a recommendation that also emerged from the literature. The research committee also felt it was important to measure the clinicians' perceptions of how well the old system worked compared to the new system. In September 1993, LGHS was awarded a \$177,000, one-year grant by the Retirement Research Foundation (RRF) to implement the pathway project. RRF indicated that, if the first year was successful, it would be interested in funding a second and third year to measure specific outcomes.

Early challenges and success strategies

Since the pathway project was implemented in January 1994, the biggest challenges have been targeting the right clients (especially in physicians' offices), using the common assessment tool, and keeping the lines of communication open. A monthly care coordinator meeting is held to share ideas, solve problems, and discuss variances to the pathways. For example, the first trend noticed on the variance forms was that physicians' orders were not being received in a timely manner for home care and nursing homes. To address this problem, pre-typed, standard orders for these sites were developed.

The orders could be individualized and then sent with the other tools to the next site (i.e., from the nursing home to home care).

Project staff have already been analyzing which pathways and sites have been successful, although it is too early to form conclusions. A key to continued growth and expansion of the project is an integrated information system. Project leaders have been evaluating an information system (Senior Information System, or SIS), which would connect the sites through personal computers and modems. This system is relatively inexpensive and eventually can be connected to the open architecture integrating system LGHS is now installing. SIS already has software that links many types of community-based providers.

Although the pathway project at LGHS is in the early stages of implementation, it has been well received. While areas for improvement have been suggested, there have been no negative comments about the project as a whole. Clinicians agree that the project is going smoothly, and, most even question why it was not undertaken sooner. A continued concern is securing resources to expand and evaluate the project.

St. Mary Medical Center

St. Mary Medical Center (SMMC), a founding member of the NCCC, has been a key force in advancing the development and implementation of extended care pathways. At SMMC, the terms "extended care pathways" and "practice parameters" are used to refer to the same tools. The sections of this case study are as follows:

- Background
- The Practice Parameter Framework
- The Move Toward Practice Parameters and ECPs
- SMMC Structure and Implementation Process
- Issues to Consider in Developing and Implementing ECPs

Background

About SMMC

SMMC is a 550-bed acute care medical center owned and operated by the Sisters of Charity of the Incarnate Word Health Care System. Hospital services include acute care, skilled nursing care, acute rehabilitation, inpatient gero-psychiatry, outpatient geriatric psychiatric partial hospitalization program, various clinics, geriatric services, and home health.

Several years ago, SMMC set out to decrease fragmentation of care and duplication of services, and to deliver care that was more patient-focused. SMMC's belief statement underscores the primacy of the patient:

Based upon a belief in the presence of Jesus Christ in every person, there is nothing more important than being available to the patient in a moment of need.

To fulfill its mission, SMMC recognized the need to create a new open environment based on the following guiding principles:

- Work will be organized with an emphasis on the needs of patients and the mission of SMMC.
- Operations will be patient-focused, with services aligned around patients and ideally positioned at the bedside.
- The staff will be autonomous and capable of delivering a full range of services, with the general mindset being, “never pass off what you can do as effectively yourself.”
- Roles will be restructured, with accountability and responsibility for high-quality and low-cost services.
- The work environment will promote a climate and cultural focus toward continuous improvement.
- The staff will be organized in multidisciplinary and self-directed work teams to provide patient care and self-management.
- All staff, regardless of position, will share in these principles.

While the creation of an open environment was to be a new structure and approach to the provision of medical care at SMMC, it was founded on a long tradition of innovation to address the changing needs of the patients served by the medical center. For example, SMMC was one of the original hospitals participating in the Medicare SHMO demonstration project. It was also the first hospital in the Los Angeles area to address the need of the AIDS population and has a nationally acclaimed geriatric assessment clinic and service delivery program.

The Practice Parameter (ECP) Framework

Six assumptions provided the framework for the development of extended care pathways and patient-focused care.

- Current nursing documentation is cumbersome and, under a traditional system accounts for approximately 35% of nurses’ time.
- Coordination between various care providers is fragmented and inconsistent.
 - New patient assessments are conducted each time a patient moves within the medical center, be it from a specialty unit to a general floor, from the general floor to skilled care or rehabilitation, or to home health.
 - Little, if any, information follows the patient. Patient medical records are often lost for a significant time in the billing department during transitions of care.
 - Patients complain that they are asked the same questions about their histories and care by subsequent nurses.
 - There is little or no sharing of information between disciplines.
- Not only is the documentation redundant, it often contains contradictions in assessment and plan of care.
- The lack of coordination and redundancy of documentation results in ill-defined plans of care that are singularly focused and not multidisciplinary. These plans of care are inadequate and often do not meet the requirements of regulatory agencies such as the JCAHCO or state licensing bureau.
- Numerous professional organizations, such as the American Medical Association, suggest that practice parameters can help coordinate care and reduce inconsistent and redundant charting.
- Surveys and early results from other medical centers indicate that physician and patient satisfaction improves if care is better coordinated.

The Move Toward Practice Parameters and ECPs

Key components

Since current documentation methods were redundant and uncoordinated between sites, the use of ECPs was expected to increase efficiency and improve the quality of care. ECPs were also expected to provide important guidance to SMMC's self-directed work teams, facilitating communication among care team members and assuring accountability for care tasks outlined in the ECPs.

Consultants' role

SMMC used the services of Booz Allen Consultants in the development and implementation of patient-focused care and practice parameters. Using consultants eased some time constraints on staff as they developed new work plans and guidelines while continuing their regular duties. The consultants also kept the teams on a time frame. Most importantly, the consultants were able to share their experience in implementing similar programs in other hospitals and help SMMC avoid repeating the mistakes of others.

Using a patient-focused care structure

The patient centers chosen for implementation were maternal child health, medicine, and surgery/neurology/orthopedics/rehabilitation. While the major focus was on acute care units, SMMC recognized the need to expand the use of practice parameters to other non-acute units, such as home health, the skilled nursing unit, acute rehabilitation, and outpatient services.

The maternal child health unit was chosen to be the prototype unit because it had few diagnoses, simple procedures, and relatively few staff and physicians. The initial structure and framework for practice parameter development and implementation were created in the prototype unit and later modified for use by the other care centers.

Practice parameter definition

As work progressed, SMMC defined a practice parameter as:

a multidisciplinary plan of care, developed for a specific diagnosis and/or problem through a multidisciplinary review of current practice, and designed to assist in the coordination of care provided to patients.

Practice parameter objectives

In addition to objectives already stated for patient-focused care, there were specific objectives for practice parameters. Parameters and associated documentation by exception were expected to:

- improve the quality and consistency of documentation and eliminate discrepancies.
- reduce time associated with documentation.
- enable the plan of care to reflect true needs and be unique to each patient.
- facilitate communication between various care providers to better define roles and job responsibilities (especially important in self-directed work teams).
- allow patient care providers to more effectively anticipate physician orders, thus assisting the physician in care decisions.

SMMC Structure and Implementation Process

About the details....

Parameter development was presented to the medical staff through the hospital's executive committee, which gave its approval of the concept. Approving specific content within individual parameters was left to the section chiefs and committees.

Each patient care center selected a multidisciplinary development team responsible for identifying which parameters would be developed. Although the centers encouraged physician support, few physicians actually participated in the process.

To determine which parameters would be developed, each patient care center reviewed the previous year's statistics, with the goal of incorporating 85% of the center's diagnoses. The centers then prioritized diagnoses by conditions that were most challenging and/or expensive.

The teams decided to use practice parameters for a specific diagnosis. In the absence of a definitive diagnosis, they decided to use a generalized practice parameter for the clinical area. Parameter supplements were created to address patients with co-morbidities (e.g., diabetes or incontinence). The supplements are similar in structure to core parameters but address only the items that would change when two conditions are present.

An oversight team was formed with a representative from each of the patient care centers. The purpose of the oversight team was to:

- facilitate and support the development and implementation process across all patient care centers.
- develop an educational approach.
- develop and implement a standardized review process to ensure clinical validity and caregiver adherence to adopted policy.
- develop a reference library for ongoing review and reference.
- identify and implement other processes that can be facilitated by practice parameters.
- be the communication link between the practice parameter effort and the hospital.

Initial construction and review

The oversight team decided on a basic format for parameter design based on prototype development in the maternal child center. The initial construct of the parameter was mainly the responsibility of the nursing staff in collaboration with other providers as necessary. Tasks included selecting DRG/patient types, selecting hospital protocols and care plans, and developing clinical content.

Charts were constructed to validate the parameter with the same diagnosis looking for content. Next, the center teams applied outcome standards, determined what other disciplines needed to review the parameter, and suggested further revisions. After the final center team revisions, the parameter was reviewed by physicians selected by the medical staff executive committee and physician department chairs.

Final review and approval

Final approval of the parameter was the responsibility of the center team and the oversight team, in collaboration with quality assurance and risk management. The practice parameters and parameter supplements were deemed ready for clinical trial upon completion of in-service training of the caregivers. After a two-week trial period, the center team reviewed the parameter again and made appropriate changes.

Upon completion of the trial and final review, the practice parameters and parameter supplements were ready for implementation. Now, during the implementation phase, there are ongoing audits for validity, consistency of use, and staff compliance. Each center team, in consultation with assigned physicians and clinical staff, must monitor ongoing use and update the parameters at least yearly. Final review remains the responsibility of the oversight team. Appendix E contains ECP materials developed by SMMC.

Issues to Consider in Developing and Implementing Extended Care Pathways

Physician buy-in

Because there are several hundred physicians at SMMC, it was simply not feasible to involve all of them in ECP development from the start. The plan for physician involvement was to inform the physician leadership of the medical executive committee's decision to move ahead with ECPs. Each patient care center was then to identify physicians to work on parameter development.

In retrospect, it would have been better to insist that the physicians attend at least one of the meetings per month and become active in the actual developmental process, not just give approval after the fact. The major fear of the physicians was that writing down a practice meant setting a standard of care by which they all would be judged. It took numerous communications from the AMA, the hospital attorney, and even an independent attorney chosen by the physicians, to reassure them that this fear was unfounded.

Portability of the prototype unit

While the maternal child care center as a model afforded the easiest implementation because of its limited number of procedures and small number of physicians, implementation has been more difficult in the other patient care centers.

Personnel issues

Practice parameters were being developed and implemented at the same time SMMC was asking staff to cross-train and expand their traditional work roles. Additionally, during this period the hospital experienced a major census decline that required some layoffs. All of these factors produced fears of job loss and created turf issues that had to be overcome. Only constant reassurance from administrative staff overcame these concerns.

Time

When the parameters were being developed on the prototype unit, there was a lot of support from consultants and other administrative, and support persons were plentiful. This support dwindled during development of parameters for the other centers, because it was thought that the previous experience would pave the way. Ongoing support was critical at this time, since staff members had to develop the parameters while carrying on with their regular jobs. One staffing miscalculation was in not allocating enough of a typist's time to prepare the documents and subsequent revisions.

Overall, the development and implementation of ECPs at SMMC has been successful, supporting the delivery of more efficient and effective care. One of the more important lessons learned was to involve physicians early and insist on their continued, active input into ECP creation and use.

Section 5: Extended Care Pathways — The Difference They Make in Patient Care

Behind the conceptual framework, the implementation process, and the evaluation methods related to extended care pathways stands the person in need of chronic care. In everyday life, fragmentation of care can result in real tragedies for such individuals.

In this section, an actual case experienced at a major health care system demonstrates what can happen when services are not integrated across service settings for a client (part A). Part B presents quite a different outcome for the same condition and client based on the implementation of an extended care pathway in a chronic care network.

The Effects of a Fragmented System - A Case Example

Mrs. P., an 87-year old female, lived independently in her own apartment. She had high blood pressure and mild emphysema but rarely saw her attending physician. She stopped taking her blood pressure medications because “she felt fine.” Her closest relatives, a niece and grandniece, maintained weekly phone contact with her and visited periodically.

One day, Mrs. P.’s apartment manager discovered her on the floor in her apartment. She was rushed to the local emergency room where they diagnosed a stroke. Since Mrs. P. herself was unresponsive, no information about medical history, family contacts (or even her physician) was immediately available. Once the apartment manager tracked down her niece, past medical history was retrieved.

Mrs. P. was admitted to a medical floor where she stabilized and became more responsive. A full medical workup was completed in a few days. She was placed on a diet and physical and occupational therapy was begun on the fourth day after admission. This is an unexplained deviation because therapy is normally started the second day after admission.

By the sixth day of Mrs. P.’s stay, she developed pneumonia due to aspiration of her food. It was discovered that a swallowing evaluation had not been conducted as part of the stroke workup. She was placed on antibiotics for the pneumonia. A feeding tube was introduced on her ninth day.

By the 13th day, Mrs. P. was doing better, so she was transferred to the rehabilitation unit. The extenuating circumstances related to Mrs. P.’s care increased the typical seven-day stay of a stroke patient on a medical unit to thirteen days.

Mrs. P. progressed well on the rehabilitation unit. She was performing simple ADLs and was able to walk with moderate assistance and a cane. After two weeks, Mrs. P. had a fever and had to be readmitted to the medical floor from the rehabilitation unit. The fever was attributed to a urinary tract infection due to an indwelling catheter that was not removed in a timely manner. Mrs. P. was given antibiotics for the infection, but physical and occupational therapy were not reordered until the fifth day after her readmission to the medical floor. When the rehabilitation unit evaluated her on her fifth day, she was too weak to tolerate their program, so instead of returning her to the unit to continue the average four-week stay, they recommended nursing home placement.

The hospital social worker/discharge planner met with the niece to discuss and assist with placement. The niece expressed surprise at the recommendation for nursing home placement and commented about how unprepared she felt to make such a decision. Mrs. P.’s niece spent two days looking at nursing homes and decided to take Mrs. P. home with her. It was later learned that this decision was based largely on the fact that Mrs. P.’s funds were tied up in CD’s that the niece did not know how to access. She did not understand that Medicare would have paid for the first 100 days of nursing home care.

Prior to Mrs. P.'s discharge, the niece received one day of limited instructions about managing tube feeding and general care for her aunt. The social worker/discharge planner arranged for home care to provide a visiting nurse, therapy and supplies. The niece should have been provided with much more intensive, hands-on instruction. Mrs. P. left the hospital on the ninth day after her second admission to the medical floor. The usual length of stay for a urinary tract infection is five to seven days.

The visiting nurse received little information about Mrs. P.'s medical history or her functional status prior to discharge. Since the niece was at work, much time during the initial RN visit was spent tracking down information from multiple sources and completing her assessment forms. The visiting nurse discovered that Mrs. P.'s niece worked all day and that care was in the hands of Mrs. P.'s grandniece, who had two small children. Mrs. P.'s family, with help from the visiting nurse and the therapists, "managed" the first week. During that time, Mrs. P. spent most of her time in bed because the grandniece could not handle walking or transferring her out of bed.

The social worker had earlier suggested adult day health service and outpatient rehabilitation as options, but the family was too overwhelmed to follow up on the suggestion. No one contacted the adult day health service to ask them to follow up with the family.

During the second week at her niece's home, Mrs. P. became increasingly lethargic, developed an elevated temperature and complained of leg pain. The visiting nurse and doctor tried to evaluate the problem and suggest a treatment plan over the phone because it was too hard to get Mrs. P. to the doctor's office.

At the end of the second week following discharge, Mrs. P. was readmitted to the hospital with severe dehydration, GI bleeding, and a blood clot in her leg. At the time of readmission she was unconscious, unstable, and her prognosis was grim. The emergency room had no current data about Mrs. P.'s medical status and no information about advanced directives, so they consulted the niece when Mrs. P. arrived. The niece was overwhelmed by the whole discussion and agreed to a "do not resuscitate" order but requested that everything else be done for Mrs. P.

Mrs. P. was admitted to the medical floor and was stabilized. The staff of the unit learned that the severe dehydration was associated with inadequate flushing of the feeding tube. Mrs. P. was receiving a new type of tube feeding formula which required more flushing and these instructions were not provided to the family. The blood clot was associated with the lack of mobility and the dehydration. The clot could not be easily treated with blood thinners because of her GI bleeding. She was also too debilitated at this time for a procedure to place a filter near the clot to prevent break-away and further complications.

Mrs. P. regained consciousness and stabilized again. The staff on the medical floor believed her potential too limited to warrant physical and occupational therapy. They did not have ready access to information about Mrs. P.'s functional level prior to this admission and also did not know that up until about three months ago she was living independently. They saw a woman who required total care and recommended nursing home placement to the niece. This time she agreed.

Mrs. P. was admitted to a nursing home ten days later. Limited medical records followed her to the facility, so once again an assessment was conducted at the time of admission. On the fourth day after admission to the nursing home, Mrs. P. became short of breath and eventually non-responsive. Since the nursing home had no information about code status and treatment wishes, Mrs. P. was sent to the emergency room. She had developed a pulmonary embolus, probably "break-off" from the clots in her leg. She was admitted to the medical floor for the fourth time and treated aggressively. Despite this treatment, she died at the hospital sixteen days after her final admission.

This is an example of fragmented and poorly coordinated care which resulted in very poor outcomes. The lack of coordination led to an inappropriate use of health care resources and increased costs. The chart will probably be reviewed by Medicare because of the frequent readmissions. The last sixteen days of care may be disallowed because they were related so directly to the previous admission.

The financial ramifications and consequences are but one consideration in this case study. This is an example of how lack of information between care settings led to a course of treatment that was not aggressive enough for a woman like Mrs. P.

Mrs. P. spent a total of 42 days in the hospital. She left a legacy of eight hospital admissions, eight medical assessments, three emergency room visits, and six nursing care plans. Fourteen physicians were involved in her care. Her charges totaled \$140,000, with only \$40,000 reimbursed.

The Effect of a Continuum of Care: A Different Scenario

Mrs. P., an 87-year old female, lived independently in her own apartment. As a member of a chronic care network, Mrs. P. had a primary care physician whom she saw regularly. Following a wellness path for seniors, the physician assessed Mrs. P.'s risk of stroke (e.g., by monitoring blood pressure) and started a preventive regimen when the risk was determined to be high. Mrs. P. received nutritional counseling and an exercise program to meet her needs. Mrs. P. also received education about the importance of medication compliance related to high blood pressure treatment.

The consistency of Mrs. P.'s care was supported by an extended care pathway which contained "triggers" to remind office staff to arrange follow-up appointments to monitor Mrs. P.'s compliance with her prevention plan. These interventions delayed and nearly prevented Mrs. P. from having a stroke.

Despite these precautions, Mrs. P. did have a stroke and was taken to the emergency room. ER staff had access to all of her medical records via an integrated information system. They knew her history, medication, and functional status, as well as her desires concerning treatment as listed on her advanced directives. This insured that her care was appropriate given her previous health history and current treatment preferences. The extended care pathway for Mrs. P. encompassed all settings and assisted staff in assuring a smooth transition from the ER to the medical floor and then to other settings.

When Mrs. P. was admitted to the medical floor, all her original information plus the emergency room records were accessed. The clinicians on the medical floor followed the stroke pathway which recommended a swallow evaluation before feedings and discontinuing the indwelling foley on the second day. This prevented Mrs. P. from developing pneumonia and a urinary tract infection. The stroke pathway also outlined early discharge planning and patient/family education issues. The family was well-prepared for Mrs. P.'s return to the home and had home care and other supportive services in place.

The visiting nurse assigned to Mrs. P. accessed Mrs. P.'s pathway and other medical records via the network's information system. The nurse consulted the pathway to assure that steps were being taken to prevent further disability. Information on the pathway also prompted her to check with the niece to see if legal counseling was needed; it was, and it was obtained. This allowed Mrs. P. to access funds to hire more home health care.

The stroke home care pathway recommended adult day health care when Mrs. P. reached a certain functional/wellness level. This was offered (and taken) as a socialization opportunity for Mrs. P. and as respite for the niece caregiver.

The pathway also advised medical staff about which outcomes to measure while she was recovering from her stroke. These data were fed back into Mrs. P.'s treatment plan. Information relating to Mrs.

P.'s pathway and outcomes was also fed into an aggregate database to assist the network in continuously improving the general stroke pathway.

Unfortunately, Mrs. P. became ill during her recuperation at home. The extended care pathway helped the visiting nurse and other providers (e.g., rehab) to arrange for the most appropriate type of care. As noted in the pathway, Mrs. P. received a home visit by a geriatric nurse practitioner. Also, the network information system provided excellent communication between the visiting nurse and the physician. These activities delayed an acute care admission for several months.

Eventually, however, Mrs. P. did require hospitalization. All her previous information and an updated plan of care from home care were accessed in the hospital. The acute care clinicians knew she was fairly functional and that the agreed-upon goal was to aggressively treat her problems, rehabilitate her back to baseline, and prevent long-term nursing home placement. She was discharged in a few days. Mrs. P. returned to her home with supportive services, consistent with the recommendations of the extended care pathway.

If a decision were made by Mrs. P. and her family to be less aggressive or no longer treated, this information would follow her to the nursing home. If she became acutely ill again, the goal would be comfort, not re-hospitalization, so her life would not be prolonged against her wishes. The network would supply the nursing home with a "comfort care only" pathway to help achieve this objective.

Throughout her episode of illness, all of Mrs. P.'s care was managed by case managers who coordinated her care, and, using the extended care pathway, guaranteed that she received the appropriate care to maintain her highest level of functioning in the most cost-effective setting. The network provided a single payer financing mechanism so all the care would be covered under one system.

Throughout her illness, it was clear that the extended care pathway was one of many things that helped her obtain the care she needed. The network's integrated information system, practitioners well-trained in chronic care, adequate health insurance, and a supportive family were among the other essential ingredients in her successful experience. It was also clear that the extended care pathway played a key role in integrating the care.

Overall, Mrs. P. was treated with dignity and respect, according to common protocols that crossed the boundaries between the doctor's office, the ER, the hospital, adult day care, rehabilitation center, and home. She and her family greatly appreciated the quality and continuity of care they received.

Appendix A: List of Related NCCC Publications

Integrating Care for Persons with Chronic Conditions outlines the principles behind the NCCC's effort to integrate primary, acute, and long-term care and the critical dimensions for establishing integrated chronic care networks.	\$35.00
Chronic Care Fact Sheet provides ten pages of facts documenting the emergence of chronic care as the most significant, fastest-growing, and highest-cost segment of health care.	\$10.00
Barriers to Integration identifies seven major goals for achieving integration, discusses barriers to achieving those goals, and offers recommendations for government, payer, and philanthropy collaboration to improve the delivery of chronic care services.	\$35.00
Risk Identification Guide describes a conceptual framework and processes for screening clients into risk categories in order to direct those at highest risk of adverse outcomes to appropriate interventions.	\$50.00
Model Risk Contract Guide identifies underlying assumptions and objectives to consider in the risk contracting process and outlines important contracting issues that encompass chronic care network principles.	\$25.00
NCCC Integrated CareLink 1994 is a compilation of twenty-two issues—and almost 300 references—of the CareLink produced in 1994. The CareLink is a biweekly synthesis of current research, provider innovations, and policy related to chronic care.	\$100.00
NCCC Integration Slides is a set of thirty slides on chronic care integration, including a representation of the forces for change, what it means to be client-centered and systems-oriented, and the key targets for systems transformation.	\$250.00

To order any of these reports, write or call:

National Chronic Care Consortium
8100 26th Avenue South, Suite 120
Bloomington, MN 55425
(612) 858-8999

Appendix B: Glossary of Terms Related to Extended Care Pathways

Algorithm: Similar to a protocol. Generally, according to *Webster's Dictionary*, a "step-by-step procedure for solving a problem or accomplishing some end."

Blueprint for extended care pathways: The developmental materials and general format of the extended care pathway. The NCCC uses the blueprint to facilitate consistency between chronic care networks. It includes the prevention of disability framework, the health status cycle, the standard components used to build specific care pathways, and summarized information about chronic conditions and associated risk factors.

Care management: A clinical process management system. It refers to the system of organizing and managing care at the clinical level within an organization or system. Care management includes those functions that define the flow of patients/clients and their interface with the clinical providers. The care management system may involve many different mechanisms which, taken together, are designed to assure that people get timely, appropriate, cost-effective care. Examples include: admission criteria for specific care units; screening to identify high risk individuals; multidisciplinary assessment teams for certain problems; use of guidelines, protocols and pathways; case management for subgroups of patients/clients; a shared clinical database and patient/client record; and CQI.

- **Integrated care management** is the management of care in a coordinated manner across the continuum so that care is seamless for the recipient, crossing the usual boundaries between professions and organizations, continuing over time, and functioning as a unified whole.
- **An integrated managed care system** is patient-focused, integrated care management with the attendant support mechanisms of integrated finance, information systems, and system management.
- **Note** that some care management programs use the name "care management" because they object to the connotations of "case" as applied to individuals. Nevertheless, they are case management programs—not care management systems.

Care pathway: A standardized approach to the multidisciplinary care of the individual in one particular setting with a particular diagnosis. It is an outcome-oriented, consensus-directed agreement. It specifies what will be done at particular points along a specified time scale in order to achieve the desired outcome. A care pathway represents a consensus of expectations for that setting and diagnosis. It is intended to be used as a tool for managing, monitoring, and evaluating care.

Care plan: A plan for care that will be provided to a particular person/client/patient that is highly individualized to that person's needs. It describes what care will be provided, and how it will be provided, including goals and a general timeline. In some settings, it covers care from many providers, such as community-based long-term care. In other settings, it may cover only one type of care (e.g., a nursing care plan in the hospital).

Case management: A function, service, or program provided to coordinate complex care for selected individuals who are more vulnerable, at greater risk, or involved in more complex problems than most. The coordination takes place across care units, disciplines, and organizations. The function itself is a clinical process performed by an individual or team. It includes the standard components of a comprehensive health and functional assessment, development of a multidisciplinary care plan, implementation of the plan, monitoring of the person and care over time, and periodic reassessment to ensure continued appropriateness of the care. While the functions of case management are standardized, the case manager's role includes individualizing the care to the recipient.

Chronic care network: A formal alliance of chronic care providers who deliver a full array of chronic care services and who work together as one seamless system to meet measurable and system-wide cost and client goals. In this client-centered system, there is an emphasis on disability prevention and the integration of care management, financing, information and network management systems. Ideally, CCNs are supported by state and federal policies that promote integrated chronic care.

Clinical care guideline/practice guideline: A consensus-derived standard for clinical care. It describes, usually in narrative form, what is appropriate, effective care; this is frequently based on a review of research findings and/or the experience of a panel of experts. It usually covers one profession. It is not specific to a setting, individual, or timeline.

Critical pathway: A label frequently used to describe a care pathway in an acute care hospital setting.

Disabling chronic conditions: Nine conditions which the NCCC has targeted for extended care pathway development. They are: Alzheimer's and related disorders, arthritis (rheumatoid and osteo), cerebral vascular disease (stroke), chronic obstructive pulmonary disease (COPD), congestive heart failure (CHF), depression, hip fractures (including osteoporosis), peripheral vascular disease, and urinary incontinence.

Extended care pathway: A set of policies and procedures used to address treatment of disabling chronic conditions. The goal is disability prevention, enabling providers to collectively prevent, delay, or reduce the onset of, or ongoing effects of, disability through the natural progression of pathology, impairment, functional limitation and disability, across time and place. Extended care pathways include primary prevention and a screening function (NCCC Component Strategy, June 1992).

Extended care pathways could be visualized as a series of care pathways that cover care for one condition in a series of settings. These pathways are jointly developed by all care providers to address the risk factors and care needs of a person with a specific condition. Such pathways identify expectations about the entire continuum of care, including transitions from one setting to the next. Conceptually and ideally, an extended care pathway should be extensive enough to specify care from the first appearance of symptoms to death (from a condition). Minimally, a care pathway must encompass two settings (including the transition between them and the transition from one source of funding to another).

General prevention: Actions and activities intended to prevent health problems in general. "Good health habits" prevent a large number of diseases. For example, refraining from smoking helps to prevent many lung and cardiac diseases, and probably others as well. Other healthy lifestyle actions include being physically active and fit, maintaining a diet that is high in fiber and low in fat or cholesterol, and participating in activities that provide personal satisfaction.

Health education: General education about leading a healthy life and specific education about various health conditions. Specific teaching/education for a person who already has a health condition is usually called "patient education."

Health status cycle: A representation of changes in health status over time from the perspective of the individual (client/patient). The cycle contains five categories (statuses): asymptomatic, symptomatic, functional decline, functional recovery and adjustment. Each category occupies a time period of unspecified and variable length. In each period, there are important tasks for the individual to accomplish, and important ways for the care system to help the individual.

Prevention of disability: The conceptual framework used by the NCCC as it designed and developed managed care and service delivery reforms (see the NCCC Component Strategy, June 1992,

for more information). Briefly, the NCCC framework describes a four-stage progression from pathology to impairment, to functional limitation, to disability. Frequently an individual possesses characteristics or encounters circumstances that put her or him at risk of becoming more disabled. The risk factors may be biological, environmental (physical and social), lifestyle, or behavioral. If the risk factors can be changed, the progression may be halted, thus preventing disability. To the extent that risk factors are known for a targeted condition, the care pathways developed at the chronic care network level should identify these factors and work to change the risk factors to prevent disability.

Primary prevention: Prevention activities that prevent the appearance of disease, such as immunizations to prevent one from getting pneumonia or influenza.

Protocol: A tool for deciding which care to provide under what circumstances. To assist in decision making, it usually contains a "decision tree" (if-then statements that follow various branches) or flow charts. It is not specific to a person, nor to a setting, and frequently covers a smaller segment of care rather than a whole illness. It describes the order in which things need to be done, but does not suggest a timeline. A protocol may be in a very brief recipe format, or it may be graphic.

Screening: The testing of apparently healthy people to see if they have a health condition before it becomes symptomatic (e.g., mammograms for women over 50 who have not detected evidence of breast cancer). Some screening has been determined to be effective in identifying conditions that would benefit from treatment even before they are symptomatic. Efforts are underway to develop a list of such tests, and an optimal schedule for performing each. Screening is part of early detection.

Standard components of extended care pathways: These are the core elements of an extended care pathway and promote consistency among chronic care networks. General categories include goals, assessment, intervention, expected outcomes, and information transfer. No single care setting (care pathway) will need all of these categories, but the list is intended to cover all possible care settings.

Appendix C: Summary Information re: Stroke

General Summary Information

Stroke is a syndrome involving neurologic deficit of relatively rapid onset produced by one of several conditions that impair circulation of blood to the brain or spinal cord. There are many causes of stroke, including infarction resulting from thrombotic or embolic occlusion of a cerebral artery, or spontaneous rupture of a vessel resulting in intracerebral or subarachnoid hemorrhage.

There can be a wide variety of impairments resulting from stroke, depending on the parts of the brain affected. The impairments may be temporary or may be permanent. It is thought that most neurological recovery takes place within six months, but patients may continue to show improvement in function for two years or more. Mortality within the first 30 days of a stroke averages 20-30% (from all causes).

The period following a stroke can be divided into three stages:

- Acute: the first 48 hours
- Rehabilitation: 48 hours to three months
- Long-term (maintenance): continuing

In one large study of stroke survivors, 52% had no motor impairment after six months, 32% were dependent in ADLs, 22% in mobility, and 56% in IADLs. Fifty-nine percent had decreased socialization outside the home, and this group included persons with no motor impairments. Nearly 30% of stroke survivors have another stroke within ten years.

Incidence/Prevalence

Nearly 500,000 U.S. citizens have a first stroke each year. The risk of stroke is strongly associated with advancing age. Of the new strokes that occur each year, 80% affect persons over age 65. After age 55, the incidence doubles with each additional decade. There has been a dramatic decline in the incidence of stroke in recent years. Survival has also increased (as has the elderly population), so there has been a rise in the prevalence of stroke in the population. There are approximately two million stroke survivors in the U.S.

Burden (Cost, Suffering)

Stroke is the third most frequent cause of death of all ages in the U.S. It is second for those over age 85.

In addition to its acute, life-threatening aspects, the occurrence of a stroke is often followed by significant negative life changes for the victim, including role loss, relocation to sheltered care settings, and increased dependency on others because of physical and cognitive disabilities. A stroke frequently disturbs an individual's ability to communicate and to interact socially in other ways with family and friends. Also important are the impacts of the stroke on the primary caregiver and other members of the family.

Appendix D: FOCUS and PDCA CQI Methods

Appendix E: ECP-Related Materials Developed at St. Mary Medical Center

Appendix F: References

- Buchner, D.M., and E.H. Wagner. "Preventing Frail Health." *Clinics in Geriatric Medicine: Health Promotion and Disease Prevention* (8), no. 1 (1992): 1-17.
- Center for Vulnerable Populations. *Health Reform and Vulnerable Populations* 2, no. 1 (March 1994): 1-10.
- "Federal Agency Awards \$3 million to Study Cost of Following Guidelines." *Medical Utilization Management* 23, no. 4 (February 16, 1995): 3-4.
- Geehr, E.D. "The Search for What Works." *Healthcare Forum Journal* (July/August 1992): 28-33.
- Health Outcomes Institute. *Introduction to the Health Outcome Institute's Outcome Management System*. Bloomington, MN: Health Outcome Institute, 1993.
- Henry Ford Health System. *CRISP Project Update*. Detroit, MI: Center for Health System Studies, 1993.
- Hospital Case Management* 1 (1993): 7-8.
- Hospital Case Management* 3, no. 5 (May 1995).
- Institute of Medicine. *Disability in America: Toward A National Agenda for Prevention*. Washington, D.C.: National Academy Press, 1991.
- Kelly, J.T., and M.C. Toepp. "Development, Evaluation, and Implementation of Medical Practice Parameters." *The Medical Staff Counselor* 6, no. 4 (1992): 45-49.
- Schwartz, J.S., and S.J. Cohen. "Changing Physician Behavior." *Primary Care Research: An Agenda for the 90s*. U.S. Department of Health and Human Services, 1990.
- White, M. "Case Management." In *Encyclopedia of Aging (2nd Edition)*, ed. G. Maddox. New York: Springer Publishing Company, in press.
- Zander, K. "Nursing Case Management: Strategic Management of Cost and Quality Outcomes." *Journal of Nursing Administration* 18, no. 5 (1988): 23-30.