



Evidence-Based Care Guideline

Chronic Care: Self-Management^a

Publication Date: March 9, 2007

Clicking on [Appendix #](#) will link to the referred page. This symbol behind a word or phrase signifies that a definition for these is available within the Glossary of Terms listed in [Appendix 1](#).

AIM Statement/Target Population*References in parentheses () Evidence strengths in []*

This guideline was created to provide evidence-based recommendations for self-management by families of children with chronic conditions in order to improve health outcomes. Some cited evidence is based on adult populations that were determined to be applicable as it relates to interactions with parents and families.

For the purpose of this guideline, chronic illness is defined as:

- a medical condition of more than 3 months duration (*Perrin 1993 [S]*) and/or;
- persistent functional limitations; and/or
- use of healthcare services beyond usual care (beyond resolvable developmental issues – e.g. preschool speech therapy) (*Stein 1999 [C]*).

Prevalence estimates of chronic illness in the U.S. pediatric population range from 13.7 to 30% (*Stein 2002 [O]*, *Perrin 1993 [S]*). Approximately 12.6 million U.S. children have a chronic physical, emotional, developmental and/or behavioral condition requiring healthcare services (*Newacheck 1998 [O]*). The population experiencing chronic illness has been identified by the Institute of Medicine as needing unique interventions to achieve high quality care (*Institute of Medicine 2001 [E]*).

Self-management is defined as the ongoing process by which an individual with a chronic illness or condition and his/her family engage in the following tasks:

- medical management – managing symptoms and promoting health
- emotional management – managing emotions commonly experienced
- role management – managing the impact of illness on functioning, interpersonal relationships, and life roles

(Lorig 2003 [S]).

Self-management requires that the patient/family have an active and central role in their care. Interventions that support self-management need to be based on the patient's/family's perceived concerns and problems.

Five core self-management skills are:

- problem solving
- decision making
- accessing appropriate resources
- forming a partnership with healthcare providers
- taking action toward health goals

(Lorig 2003 [S]).

Goals of self-management are to optimize health status and quality of life. Self-management is an integral component of the Chronic Care Model (CCM) (see [Appendix 2](#)), which serves as a framework for organizing and delivering health care across the continuum of care (*Tsai 2005 [M]*, *Greene 2005 [C]*, *Dorr 2006 [D]*, *Wagner 1999 [O]*, *Wagner 1996 [S]*, *Wagner 1998 [E]*).

Target Users

- Healthcare providers caring for children and adolescents diagnosed with a chronic condition, including, *but not limited to* (in alphabetical order):
 - advanced practice nurses
 - chaplains
 - child life specialists
 - dietitians
 - nurses
 - pharmacists
 - physicians
 - psychologists
 - social workers
 - therapists
- Patients and families
- Community-based personnel (teachers, case workers, etc.)

Introduction

Childhood chronic illness has many manifestations based on the developmental and cognitive levels of the child, diagnosis, disease severity and any existing comorbidities. However, the nature of living with any

^a Please cite as: **Chronic Care: Self-Management Guideline Team, Cincinnati Children's Hospital Medical Center:** Evidence-based care guideline for Chronic Care: Self-Management, www.cincinnatichildrens.org/svc/alpha/h/health-policy/ev-based/chronic-care.htm, Guideline 30, pages 1-32, March 9, 2007.

chronic illness or condition has enough similarities that
Model of 5 A's Cycle to Integrate Self-Management Into Patient Care

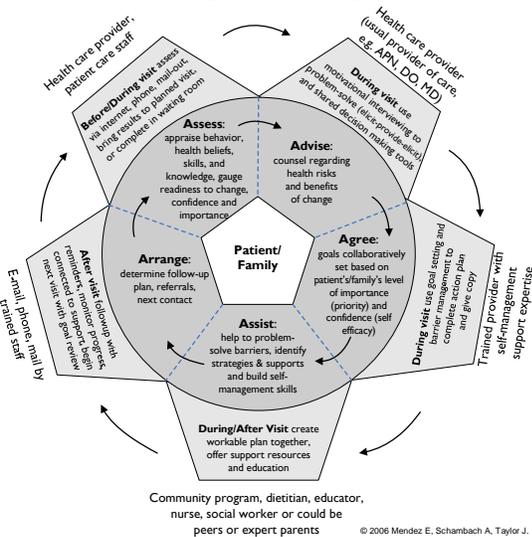


Figure 1: See [Appendix 3](#). Created from concepts originally identified by (Manley 1991 [E]).

support and care to promote optimal health outcomes from a family-centered, holistic perspective including considerations of intellectual, emotional, social, financial, physical, and spiritual well being.

The behavior change counseling model known as the **5 A's Cycle (Assess, Advise, Agree, Assist, Arrange)** was adopted for this guideline as a method to organize self-management interventions. Figure 1 is a model that was created from concepts originally identified by (Manley 1991 [E]). This model can be used during a clinic visit for designing activities to support behavior change (Glasgow 2004 [S], Whitlock 2002 [S]).

Guideline Recommendations

Information on the process for developing this guideline is found on page 26 and refer to details found in [Appendices 4, 5, 6, and 7](#).

Foundational care principles are addressed in recommendations 1 through 4, followed by more specific strategies.

1. It is recommended that the following components of comprehensive chronic care be included for all children and adolescents with chronic conditions:
 - self-management in the home/community [\[E\]](#)
 - case/care management [\[E\]](#)
 - disease specific care management [\[E\]](#)

(Norris 2002a [M], Norris 2002b [M], Norris 2002c [M], Renders 2001 [M], Wagner 2005 [S], Task Force on Community Preventive Services 2002 [S, E], Drotar 2001 [E]).

it is possible to generate common recommendations for

2. It is recommended that healthcare providers use collaborative communication [\[E\]](#) to promote patient/family-centered health care [\[E\]](#) (Michie 2003 [M], Lewin 2001 [M], Stewart 1995 [M], Wasson 2006 [C], Wasson 2006 [O], Task Force on Community Preventive Services 2002 [S, E]).
3. It is recommended that self-management interactions and interventions with patients and families be grounded in cultural competence [\[E\]](#):
 - sociocultural factors (e.g. ethnicity, social support structures, economic factors)
 - literacy level (i.e. use of linguistically appropriate educational materials)
 - spiritual tradition
 - gender and age
 - health beliefs and values
 - communication (e.g. language barriers)

(Coffman 2004 [M], Betancourt 2002 [S], Flores 2000 [S]).
4. It is recommended that healthcare teams have staff trained in the delivery of self-management strategies (Lozano 2004 [A], Clark 1998 [B], Lorig 2003 [S], Wagner 1996 [S], Local Consensus [E]).

Note 1: Content of healthcare provider education and training to include at a minimum:

- assessment skills
- motivational interviewing [\[E\]](#)
- information sharing
- problem solving/goal setting [\[E\]](#)
- shared decision making [\[E\]](#)
- self efficacy assessment [\[E\]](#)
- follow-up interventions

Note 2: Healthcare provider education on self-management strategies, provided by clinician peer leaders is effective for improving chronic care (Lozano 2004 [A], Greene 2005 [C]).

Note 3: Self-management training models, programs or resources are listed in [Appendix 8](#) (Local Consensus [E]) and [Appendix 9](#) (sample algorithm).

THE 5 A's CYCLE: ASSESS

Assess patient's and family's behavior, health beliefs, health status, skills, and knowledge.

5. It is recommended that comprehensive assessments (upon initial diagnosis or early in care management) and reassessments, using validated tools when available, be performed to evaluate the patient's/family's:

- health related quality of life [\[E\]](#)
- knowledge of disease, treatment plan, and prognosis
- family functioning
- social/environmental context (health risks)

(Hauser 1990 [C], Jacobson 1990 [C], Hauser 1986 [C], McQuaid 2005 [O], Jacobson 1987 [O], Burroughs 1997 [S]).

Note 1: These assessments will help to identify patients and families at risk for suboptimal health outcomes and poor adherence and help to stratify intensity of care management based on individual patient/family needs and risks (Norris 2002b [M], Dorr 2006 [D], Farmer 2004 [O], Burroughs 1997 [S]).

Note 2: Family conflict and the degree of parental involvement are aspects of family functioning which have been shown to be predictors of poor adherence among adolescents with diabetes (Anderson 1997 [C], Hauser 1990 [C]).

Note 3: Samples of assessment tools are found in [Appendix 10](#). Clinicians are encouraged to evaluate the validity and reliability of tools prior to their use with specific populations and/or settings. A suggested list of criteria to assess tool validity is found in [Appendix 11](#).

6. It is recommended that the following self-management components be assessed and documented:

- health beliefs
- readiness to change (motivation) [\[E\]](#) using a visual numeric scale
- confidence (self efficacy) [\[E\]](#) using a visual numeric scale
- importance (priority) [\[E\]](#) using a visual numeric scale

(see [Appendix 12](#))

(Littlefield 1992 [C], Hauser 1990 [C], Jacobson 1990 [C], Hauser 1986 [C], Hesse 2006 [O], Lorig 1989 [O], Jacobson 1987 [O], Lorig 2003 [S], Rollnick 1999 [E], Local Consensus [E]).

Note 1: Subject ratings of confidence (self efficacy) were found to consistently predict

subsequent health related outcomes (Holden 1991 [M]).

Note 2: These particular assessment components have been found to be helpful in customizing strategies in facilitating healthy behavior change.

Note 3: Samples of assessment tools are found in [Appendix 10](#).

THE 5 A's CYCLE: ADVISE/COUNSEL

Counsel patients/families by providing specific information about health risks and benefits of change

7. It is recommended that motivational interviewing be used to counsel patients/families on health behavior change (Hetteima 2005 [M], Rubak 2005 [M], Dunn 2001 [M], Lewin 2001 [M], Butler 1999 [A], Monti 1999 [B], Colby 1998 [B], Erickson 2005 [S], Miller 2002 [E], Rollnick 1999 [E]).

Note 1: Motivational interviewing [\[E\]](#) is a patient-centered, directive method of communication used throughout self-management support with the goal of enhancing motivation to change behavior by exploring and resolving ambivalence [\[E\]](#) (Miller 2002 [E]).

Note 2: Motivational interviewing is effective in brief encounters and produces better outcomes in management of unhealthy behaviors than traditional advice giving or confrontation when addressing self-management support (Rubak 2005 [M]).

Note 3: The Elicit-Provide-Elicit method is a motivational interviewing technique to structure the process for counseling patients and families in the context of a brief office visit is found in [Appendix 13](#) (Mash 2004 [O], Gance-Cleveland 2005 [S], Rollnick 1999 [E]).

8. It is recommended that shared decision making [\[E\]](#) and decision aids [\[E\]](#) (tools) be used regarding intervention options (O'Connor 2003 [M], Charles 2006 [S]).

Note 1: See sample generic decision aid tools on the web:

http://decisionaid.ohri.ca/AZsearch.php?Topic=Any_decision and

http://www.dhmc.org/webpage.cfm?site_id=2&org_id=108&gsec_id=0&sec_id=0&item_id=2486

Note 2: Shared decision making is especially beneficial when there is no clear "best" treatment option.

Note 3: Shared decision aids [\[E\]](#) produce increased confidence, knowledge and optimism, congruence with treatment, and improved

involvement in making choices regarding care options (O'Connor 2003 [M]).

THE 5 A's CYCLE: AGREE

Agreement on goals that are collaboratively set based on patient's/family's level of importance (priority) and confidence (self efficacy) in their ability to change the behavior.

9. It is recommended that written action plans  including goal setting and barrier management be used to assist patients/families in planning for behavioral change, customizing them to address:
- individual needs
 - patient characteristics
 - developmental level of the child
 - patient preferences
 - available resources
- (Haynes 2005 [M], Gibson 2004 [M], Haby 2004 [M], Toelle 2004 [M], Powell 2003 [M], Wolf 2003 [M], Staab 2006 [A], Local Consensus [E]).

Note 1: There is no consistent evidence that written plans alone produced better patient outcomes than no written plan. However, comprehensive care that includes education, a written self-management plan and regular review has been shown to improve outcomes (Gibson 2004 [M], Toelle 2004 [M]).

Note 2: The “My personal action plan” tool, found in [Appendix 14](#), is one that could be used to implement this recommendation (Local Consensus [E]).

THE 5 A's CYCLE: ASSIST

Assist patients/families to problem solve by identifying personal barriers; strategies; social, environmental, and community support and resources.

10. It is recommended that self-management education and skills building be integrated into the care of all patients/families at the developmentally appropriate level (Gibson 2004 [M], Wolf 2003 [M], Fireman 1981 [C], Task Force on Community Preventive Services 2002 [S, E], Betz 2000 [S]).
- Note 1:** Self-management education of patients and families reduces the number of hospitalizations, emergency and unscheduled visits, and missed work and school days (Gibson 2004 [M]).
- Note 2:** Patient education alone is not sufficient to promote health behavior (Norris 2006 [M], Haby 2004 [M], Bartholomew 1991 [O]).
- Note 3:** See [Appendix 15](#) for possible self-management supports at various developmental stages.

11. It is recommended that self-management education and skills building include tailored health education  based on individual patient/family needs, risks, and readiness to change (Norris 2002b [M], Dorr 2006 [D], Farmer 2004 [O], Local Consensus [E]).

Note: In randomized trials of smoking cessation interventions, tailored educational materials had the most significant impact on behavior change (Lancaster 2005 [M]).

12. It is recommended that education on self-management skills building be provided through a range of individual and/or group sessions within a variety of community settings (e.g. homes, schools, churches, camps, and worksites) beyond an office visit (Deakin 2005 [M], Gibson 2004 [M], Norris 2002c [M], Evans 2001 [A], Resnicow 2001 [A], Lorig 1999 [A], Hederos 2005 [B], Fireman 1981 [C], Glasgow 2004 [S]).

Note 1: Group-based training and nurse education improve effective home management (reduces symptoms, exacerbations, school absenteeism, and number of hospitalizations and emergency room visits) (Fireman 1981 [C]). Group-based self-management education has been shown to decrease both healthcare costs and resource utilization while improving health outcomes (Deakin 2005 [M], Hederos 2005 [B]).

Note 2: Heterogeneous patient groups are feasible and beneficial beyond usual care, can improve health outcomes and may result in more effective use of resources (Lorig 1999 [A]).

Note 3: Self-management and written health education materials which were administered and brought home from school positively influenced parent's and children's self-management of their asthma. (Evans 2001 [A], Evans 1987 [C])

13. It is recommended that peers (parents, patients, or lay experts) be involved in the delivery of self-management education programs (Chernoff 2002 [A], Von Korff 1998 [A], Anderson 1989 [B], Lorig 1986 [B], Lorig 2001 [C], Cohen 1986 [C], Story 2002 [O]).

Note: Peer-led manualized (standardized) education programs for promoting self-management of chronic disease have been found to improve health outcomes, increase patient/family support, while reducing healthcare costs and resource utilization in diverse populations and have been shown to be as effective as those led by healthcare providers (Von Korff 1998 [A], Lorig 1986 [B], Lorig 2001 [C], Cohen 1986 [C]).

14. It is recommended that computer-based information packages for patients and/or systematic mailings be used to enhance self-management education (*Kroeze 2006 [M], Murray 2005 [M], Lorig 2004 [A], Lorig 2002 [A], Glasgow 1997 [A], Horan 1990 [B]*).

Note 1: Computerized information packages for patients have been termed Interactive Health Communication Applications (IHCAs)  and have been found to:

- provide health information (increase knowledge)
- enable informed decision making
- promote healthy behaviors
- promote peer support (increase social support)
- manage demand for health services
- improve health outcomes (*Murray 2005 [M]*).

Note 2: Computer-assisted assessment that provides immediate feedback on key barriers to self-management, goal setting and problem-solving counseling has been found to improve health behavioral change and outcomes (*Glasgow 1997 [A]*).

Note 3: Systematic mailings improve role function, decrease disability and improve self efficacy and decrease the human resource cost of delivering this information (*Lorig 2004 [A]*).

15. It is recommended that the following self-management tools/interventions be incorporated into self-management support:

- self monitoring  (diaries, journals)
- action planning (written action plans 
- collaborative problem solving 
- regular practitioner review/follow up

(*Kroeze 2006 [M], Gibson 2004 [M], Powell 2003 [M], Renders 2001 [M], Lozano 2004 [A], Von Korff 1998 [A], Wasson 2006 [C], Wasson 2006 [O], Glasgow 2002 [O]*).

16. It is recommended that family-to-family support be included as an integral component of care and that “experienced” patients/families be empowered to deliver these interventions (*Chernoff 2002 [A], Ritchie 2000 [A], Von Korff 1998 [A], Hederos 2005 [B], Lorig 1986 [B], Cohen 1986 [C], Burroughs 1997 [S]*).

Note 1: Family-to-family support has been shown to decrease anxiety and worry in caring for children with chronic health conditions (*Irey 2001 [S]*).

Note 2: Examples of family support interventions may include: family-to-family networking, parent mentoring, web-based

communication, patient/family newsletter, and/or parent advisory teams.

17. It is recommended that children, adolescents, and their families be referred to trained professionals to implement any of the following interventions:

- family therapy
- stress management
- coping skills training
- relaxation and cognitive behavioral therapy
- behavioral incentives 

(*Yorke 2005 [M], Eccleston 2004 [M], Lemanek 2001 [M], Kashikar-Zuck 2005 [B], Burkhart 2002 [B], Degotardi 2005 [C]*).

Note 1: These techniques have been shown to be effective in the management of patients with chronic pain, headache and asthma (*Yorke 2005 [M], Eccleston 2004 [M]*).

Note 2: Intense family therapy has been shown to improve outcomes in adolescents with poorly controlled insulin-dependent diabetes (*Ellis 2005 [B]*).

Note 3: Behavioral Family Systems Therapy (BFST) has been shown to improve diabetic outcomes, parent and adolescent relationships, and treatment adherence (*Wysocki 2006 [A], Wysocki 2000 [A], Wysocki 2006 [S]*).

Note 4: Behavioral incentives (e.g. praise, stickers, special activities, toys, games, gift certificates, or monetary rewards) have been shown to improve treatment adherence in children with chronic illness (*Lemanek 2001 [M]*).

THE 5 A’s CYCLE: ARRANGE

Determine and arrange for a specific follow-up plan.

18. It is recommended that self-management interactions and re-assessments occur on a regular, structured basis (*Haynes 2005 [M], Gibson 2004 [M], Powell 2003 [M], Renders 2001 [M], Hauser 1990 [C], Jacobson 1990 [C], Hauser 1986 [C], Jacobson 1987 [O]*).

Note 1: Available evidence does not well define the optimal level of intensity or frequency for these interactions. In one meta-analysis of adults with type 2 diabetes, increased contact time between educator and patient was the only significant predictor of improved glycemic control (*Norris 2002a [M]*).

Note 2: Evidence indicates that decreased intensity or frequency of clinical review may negatively impact the effectiveness of self-management (*Powell 2003 [M]*).

Note 3: Frequent contacts (email, phone, office visit) between provider and patient/family are

an effective method of enhancing adherence. More complex interventions do not necessarily produce better outcomes (*Haynes 2005 [M]*).

Future Research Agenda

1. What intensity of intervention (how soon after diagnosis, initial time spent, periodic follow up) is required to produce measurable improvement in health status? In self efficacy? In specific outcomes?
2. Which healthcare personnel or providers (lay/peer?) are best suited to providing self-management support?
3. What communication/interactional models are most effective in ensuring healthy behaviors in children with chronic illness?
4. What method is best for determining which interventions have the greatest impact on creating optimal health in children with chronic illness?
5. What cost savings (if any) can be realized by using a self-management approach?
6. Is self-management support best offered in a one-to-one clinic setting or in an educational group setting?
7. Methodically sound and theoretically consistent intervention studies are needed to assess staged-based approaches to behavior change (*Riemsma 2002 [M]*).
8. Further research is needed to: (1) standardize reporting of complex interventions; (2) extend and update these types of reviews; (3) improve identification of patients at risk from their various chronic conditions; (4) develop and test appropriate outcome measures for various chronic conditions; and (5) design and evaluate, via the conduct of high-quality pragmatic randomized controlled trials (RCTs), more powerful psychoeducational interventions that are conceptualized in terms of the ways in which psychosocial factors and various chronic conditions interact (*Smith 2005 [M]*, *Denboba 2006 [O]*, *Schneiderman 2001 [S]*).
9. Research into the broadest theoretical frameworks for care within the larger community is essential to determine the most effective population health improvements (*Jack 2004 [M]*).
10. The majority of cultural competence studies have been completed since 1995. This alone speaks for the urgent need for continued research into qualitative work and intervention studies in order to enhance the knowledge base of healthcare providers in this area (*Coffman 2004 [M]*).
11. The effects of involving consumers in developing healthcare policy and research, evidence-based care guidelines and patient information material remain largely unevaluated, though such efforts are feasible (*Nilsen 2006 [M]*). Further studies are needed to address:
 - methods for recruiting consumers
 - degrees of involvement (relationship between consumers and providers)
 - forums for communication
 - consumer involvement in decision making
 - ways of providing training and support
 - degrees of financial support.

Appendix 1: Glossary of Terms

(Glossary page 1 of 3)

To augment clarity in guideline recommendation verbiage, it is encouraged that readers use the glossary of terms as needed. Terms are listed in alphabetical order. Web links are added where helpful to obtain deeper levels of information or to cite a source.

Ambivalence – The coexistence within one person of contradictory and incompatible emotions or attitudes and the tension arising as a consequence (Miller 2002 [E]).

Behavioral incentives – Rewards for a specific behavior; designed to encourage agreed upon behavior.

Care management – Sometimes used interchangeably with case management, but care management is often used as a broader, more holistic term. A system of coordinated healthcare interventions and communications for populations with conditions in which patient self care efforts are significant. This comprehensive approach includes the following care components: population identification processes, collaborative practice models; patient self-management education; routine reporting/feedback involving patients; families, physicians, plan and care teams; and process and outcomes measurement while emphasizing prevention of exacerbations and complications using evidence-based practice guidelines and patient empowerment strategies; and evaluating clinical, humanistic, and economic outcomes on an ongoing basis with the goal of improving overall health. See also “Case management and Disease-specific care management.” <http://www.scotland.gov.uk/publications/2006/05/16081604/2> and <http://www.archive.official-documents.co.uk/document/cm41/4192/v3ch5.pdf>

Case management – Monitoring and coordinating the delivery of health services for individual patients to enhance care and manage costs; often used for patients with specific diagnoses or who require high-cost or extensive healthcare services. A process to manage and coordinate healthcare resources used in the provision of services. See also “Care management and Disease-specific care management.” <http://www.cmsa.org.au/definition.htm>. and <http://wwwccmcertification.org/pages/136body.html>.

Collaborative communication – Consists of multidisciplinary interactions that facilitate common, positive patient care outcomes based on a respectful and trustful relationship (Reimanis 2001 [S]). Principles of collaboration in health care include: understanding of patients’ beliefs, wishes and circumstances; understanding of family beliefs and needs; identification of a single person to be the main link with each patient; collaborative definition of problems and goals; negotiated agreed upon plans and goals regularly reviewed; active follow up with patients and regular team review (Wagner 1996 [S]).

Confidence – Refers to a person’s belief in his/her ability to master a particular behavior change in a variety of circumstances and to maintain that change over time (Rollnick 1999 [E]).

Continuum of care – Matching the participant’s ongoing needs with the appropriate level and type of medical, psychological, health, or social care or service within an organization or across multiple organizations. <http://aspe.hhs.gov/daltcp/diction.shtml#continuum> and <http://www.chcr.brown.edu/pcoc/contin.htm>

Cultural competence – Cultural and linguistic competence is a set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among healthcare providers that enables effective work in cross-cultural situations. Cultural competence in health care describes the ability of systems to provide care to patients with diverse values, beliefs and behaviors, including tailoring delivery to meet patients’ sociocultural and linguistic needs (Betancourt 2002 [S]). For more information: <http://www.omhrc.gov/>

Decision aids – Interventions designed to help people make specific and deliberative choices among options (including status quo) by providing (at a minimum) information on the options and outcomes relevant to a person's health status (O'Connor 2003 [M]). See examples on the web: <http://decisionaid.ohri.ca/AZinvent.php> and http://www.dhmc.org/webpage.cfm?site_id=2&org_id=108&gsec_id=0&sec_id=0&item_id=2486.

Delphi Method – A systematic group technique that uses anonymous responses from experts and feedback summaries of the responses in order to build or achieve consensus or focus. Responses are obtained through a number of cycles of anonymous replies to the facilitator (or leaders). Responses are collected and analyzed to identify common (or conflicting) viewpoints or themes. Process concludes when common themes have emerged.

Appendix 1 Glossary of Terms

(Glossary page 2 of 3)

Disease-specific care management – An interdisciplinary, continuum-based approach to healthcare delivery that prevents, minimizes, or delays exacerbations or complications of an illness or condition by:

- supporting the participant’s self-management activities;
- supporting the ongoing patient-practitioner relationship;
- using a standardized method or process for delivering or facilitating the delivery of clinical care based on evidence-based care guidelines;
- tailoring treatments and interventions to the participant’s need;
- promoting the flow of patient information across settings and providers while protecting patient rights, security, and privacy;
- analyzing and using data to continually revise treatment plans; and
- continuously evaluating ways to improve performance and clinical practice, thereby improving participant care (DSCCM).

See also “Care management and Case management .” http://www.dmaa.org/dm_definition.asp

Readers interested in **care/case management or disease management** may find some direction on these components at:

- <http://www.improvingchroniccare.org/>
- www.dmaa.org
- www.cmsa.org
- <http://intermountainhealthcare.org/xp/public>

Goal setting – Setting a specific healthcare goal with a desired outcome to be achieved in a specific time frame. This can be used as a source or method of motivation <http://www.mindtools.com/page6.html>. See also “Problem solving.”

Health-related quality of life (HRQOL) – A consensus has emerged that HRQOL is multidimensional and includes four core domains: 1) disease state and physical symptoms, 2) functional status, 3) psychological and emotional functioning, and 4) social functioning (Aaronson 1992 [E]). It is also patient-oriented, rather than physician-oriented, reflecting the individual’s subjective evaluation of his or her daily functioning and well being (Spilker 1996 [E]). Furthermore, rigorous standards of measurement development and psychometric analysis have been applied to measures of HRQOL (Ware 1992 [O], Aaronson 1992 [E]).

Health status – The functional well being of specific populations, both in general and in relation to specific conditions, that (for example, physical functioning, bodily pain, social functioning, mental health).

http://healthfieldmedicare.suite101.com/article.cfm/health_status

Importance – Refers to a person’s feeling, views, and values on whether a change will lead to an improvement. A tool that has had some validation study in measuring this construct includes a visual analogue scale assessing importance (Rollnick 1999 [E]). See [Appendix 12](#).

Interactive Health Communication Applications (IHCAs) – Computer-based, usually web based, information packages for patients that combine health information with at least one of social support, decision support, or behavior change support (Murray 2005 [M]).

Motivation – Refers to a person’s expressed degree of readiness to change. It is the psychological feature that arouses an individual to purposeful action in initiating, directing, and persisting in behavior toward achieving a desired goal (Miller 2002 [E]).

Motivational interviewing – A patient-centered, directive method of communicating with the goal of enhancing intrinsic motivation to change by exploring and resolving ambivalence (Miller 2002 [E]). <http://www.motivationalinterview.org/sitemap.html>

Nominal Group Technique – A structured face-to-face group process technique for gaining consensus. The process prevents the domination of discussion by a single person and encourages all group members to participate. The process concludes and results in a set of prioritized and scored focus areas, solutions or recommendations.

Patient activation – A central concept to consumer-driven health care and the chronic care model involving four stages: (1) believing the patient role is important; (2) having the confidence and knowledge necessary to take action; (3) taking action to maintain and improve one’s health; (4) staying the course even under stress. Evidence indicates that active involvement by patients and families leading to a management treatment plans structured around their lifestyle and beliefs are more likely to produce good health outcomes. “The ‘patient activation’ approach may encourage patients to set their own goals and develop their own plans for achieving them. It may also engender self efficacy in the patient that will help them implement their plans and achieve their goals” (Michie 2003 [M], Hibbard 2005 [O], Hibbard 2004 [O]). Use of the Patient Activation Measure (PAM) tool is available by permission at: <http://darkwing.uoregon.edu/%7Ejhibbard/licenseinfo.htm>.

Patient/family-centered health care – An innovative approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among patients, families, and healthcare providers, refers to patients of all ages, and may be practiced in any healthcare setting <http://www.familycenteredcare.org>. It has also been suggested that there are “two separable but important ingredients of patient centeredness. These are (1) the ability to elicit and discuss patients’ beliefs and (2) the ability to activate the patient to take control in the consultation and/or in the management of their illness” (Michie 2003 [M]).

Appendix 1 Glossary of Terms

(Glossary page 3 of 3)

Problem solving – Methods that focus on recognizing and identifying specific problems and then brainstorming possible solutions as well as barriers to solutions. Problem solving process in self-management:

1. identify the problem
2. list all possible solutions
3. choose a possible solution
4. try it for two weeks
5. if it doesn't work, try another possible solution
6. if that doesn't work, find a resource for new ideas
7. if that doesn't work, accept that the problem may not be solvable right now.

<http://www.improvingchroniccare.org/>

See also “Goal setting.”

Readiness to change – A state of mind which reflects a person's inclination towards making decisions and behavior changes in their everyday lives (Rollnick 1999 [E]). A tool that has had some validation study in measuring this construct includes the “Readiness to Change Ruler.” See [Appendix 12](#).

Self efficacy – A construct introduced by Bandura defined as an individual's estimate or personal judgment of his or her own ability to succeed in reaching a specific goal and further defined as people's judgments of their capabilities to organize and execute courses of action required to attain designated types of performances. It is concerned not with the skills one has but with judgments of what one can do with whatever skills one possesses (Bandura 1997 [E]). A tool that has had been validated in measuring this construct includes the General Perceived Self Efficacy scale (GSE) developed by Matthias Jerusalem and Ralf Schwarzer which can be accessed at <http://userpage.fu-berlin.de/~health/selfscal.htm>. In addition, many disease-specific self efficacy scales have been developed.

Self monitoring – Observing and recording one's own behaviors, actions, thoughts, and feelings about oneself, interactions or activities (examples would include daily log of blood glucose levels, exercises, treatments, diets or calorie intake, etc.).

Self-management – a daily process by which an individual with a chronic illness or condition engages in activities that protect and promote health, monitoring and managing of symptoms and signs of illness, managing the impacts of illness on functioning, emotions and interpersonal relationships and adhering to treatment regimes with the desired outcomes of improved health status and/or slowed deterioration (Lorig 2003 [S]).

Shared decision making/shared decision aids – Shared decision making is the process of interacting with patients to make informed values-based choices when options have features that patients value differently. Caregivers and patients/families come to an agreement about a healthcare decision. It is especially useful when there is no clear “best” treatment option. Patient decision aids are evidence-based tools designed to facilitate the process of shared decision making (O'Connor 2004 [S]).

See examples on the web: <http://decisionaid.ohri.ca/AZinvent.php> and http://www.dhmc.org/webpage.cfm?site_id=2&org_id=108&gsec_id=0&sec_id=0&item_id=2486.

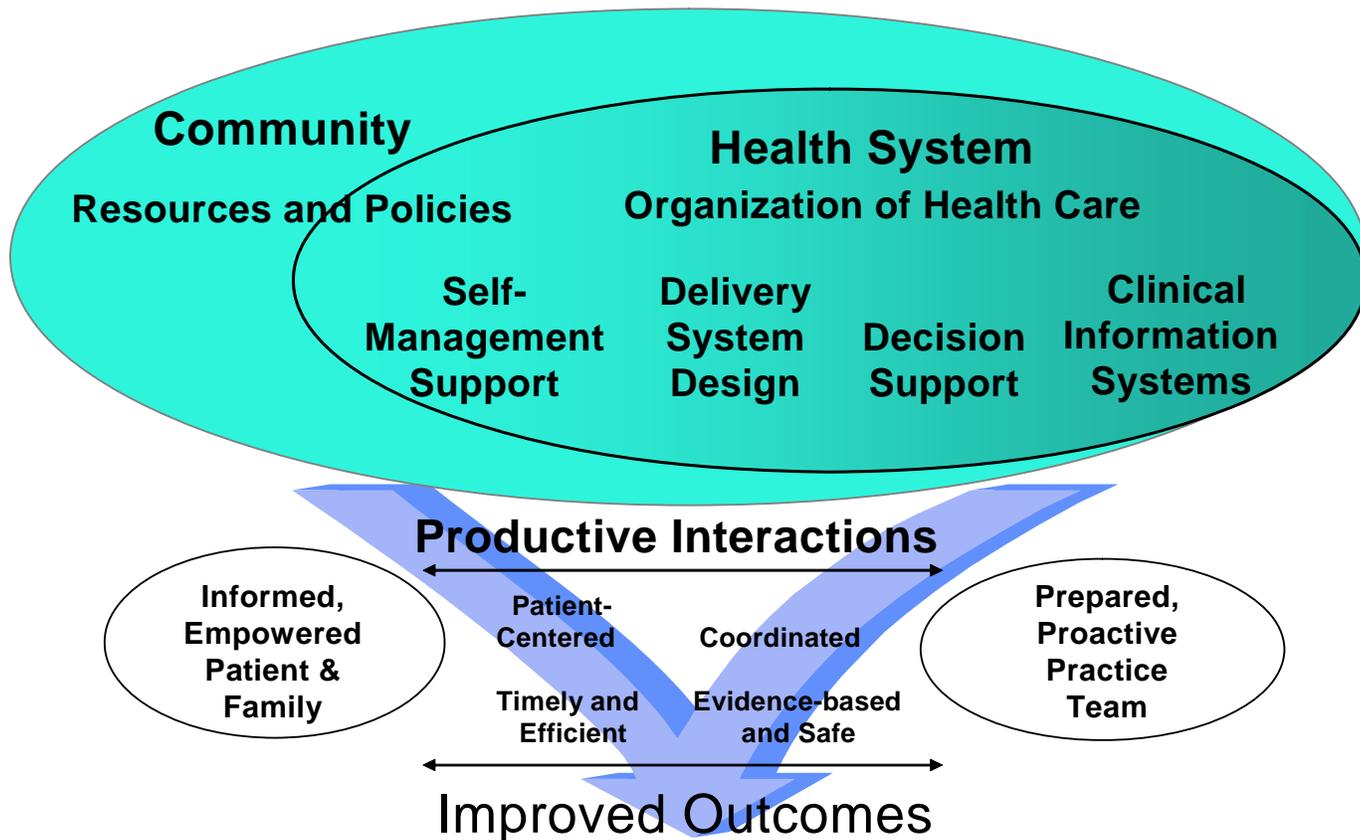
Tailored health education – A process of creating individualized communication based on a person's unique needs and specific concerns. It is an assessment-based approach in which the person provides personal data related to health behaviors and the data are used to determine the most appropriate information or strategies for intervention.

Written action plan – An individualized written plan or set of instructions that is designed for the purpose of self-management of a disease/condition or symptoms. The Written Action Plan is developed in collaboration with a healthcare provider. Examples of what the plan may include are: a list of symptoms to watch for and what to do if they occur, what aggravates or triggers the person's symptoms and how to avoid these triggers if possible, and the names and doses of medications the person needs and when to use them (Haynes 2005 [M], Gibson 2004 [M], Haby 2004 [M], Powell 2003 [M], Wolf 2003 [M], Local Consensus [E]).

Appendix 2: Chronic Care Model

The Chronic Care Model

(MacColl Institute, Wagner and Associates)

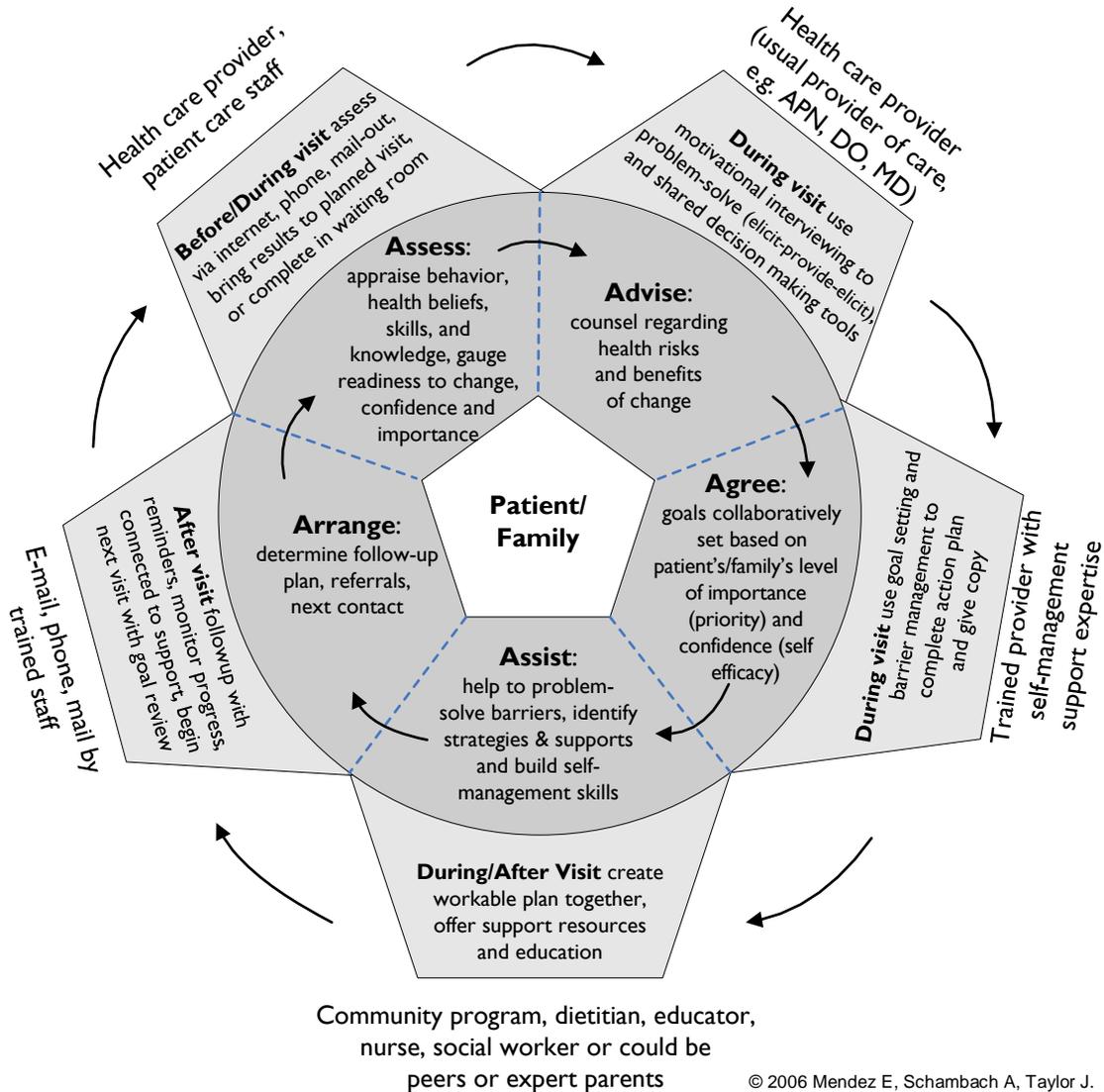


Adapted from (Wagner 1998 [E]). Used with permission.

Appendix 3: The 5 A's Cycle Model

Created from concepts originally identified by (Manley 1991 [E]).

Model of 5 A's Cycle to Integrate Self-Management Into Patient Care



Appendix 4: Priority Rankings Obtained through Delphi Method and Nominal Group Technique to Determine the Priority Domain of Focus

Delphi Results and Analysis

Breakdown by Responder Type of those who gave feedback

Responder Type	#	% of Total Responders	#	%
Patient/Parent Advisory Committee	16	31.4%	23	45.1%
Patient/Parent Clinic	7	13.7%		
Healthcare Professional	15	29.4%		
Nurse on Guideline	4	7.8%	7	13.7%
Nurse CC Team Leader	3	5.9%		
Physician CC Team Leader	3	5.9%	6	11.8%
Physician on Guideline	3	5.9%		
Grand Total	51	100.0%		

Response Rate= 98%, 54 of 55, yet **True usable data was 93%** of those who received survey, 51 of 55.

change the outcome®

Note 1: There were 2 Health Care Professionals and 1 Parent from Family Advisory Committee responder types whose survey feedback was not themeable as for the most part was list of chronic conditions (ie. CF, Diabetes, Asthma)
Note 2: Only one responder was a patient (an adult, >18 y.o.) who was personally surveyed/ interviewed.



Frequency Distribution & % of Total feedback for Theme that emerged from Aspects of Care that were listed by ALL those providing feedback

Theme	Aspects of care that were coded in this theme	% of total for this theme
Effective Management at Home	96	40.3%
Communication / Collaboration	32	13.4%
Care Coordination	24	10.1%
Effective Provider Management	18	7.6%
Patient Education	14	5.9%
Patient Factors	13	5.5%
Patient Access	12	5.0%
Effective Policies	9	3.8%
Transition to Adulthood	9	3.8%
Highly Effective Therapies	6	2.5%
Provider Training	5	2.1%
Total	238	100.0%

change the outcome®



Top 4 themes that emerged by Highest Priority Ranking from the Aspects of Care give by each of 51 responders

Theme	# of Responders who gave Highest Priority to any of their Aspects of Care that were coded into this Theme	% of 51 responders	Total Rank Score
Effective Management at Home	15	29.4%	75
Communication / Collaboration	11	21.6%	55
Effective Provider Management	8	15.7%	40
Care Coordination	6	11.8%	30
Total	40	78.5%	

change the outcome®



Appendix 5: Definitions and Elaborations for Top Four Themes in Order of Importance to Our Families and Healthcare Providers Who Were Surveyed/Interviewed in Guideline Pre-Work

Prior to organizing our Chronic Care Guideline Team, the co-chairs sought to understand more fully the personal nature of the needs of children and families experiencing chronic illness. Interviews and surveys were conducted with 51 parents, patients and healthcare providers. The themes that emerged from this preparatory work helped to direct the guideline focus. The top four themes in order of importance as ranked by our families and healthcare providers who were surveyed and interviewed are:

- I. Effective Home Management
- II. Communication/Collaboration
- III. Care Coordination
- IV. Effective Provider Management

From the interviews, descriptions of effective home management included the ability to manage daily activities, treatment regimens, symptom management, etc. on a day-to-day basis. Application of consensus techniques (Delphi Method and Nominal Group Technique) with our guideline Team members resulted in identification of self-management support and capability building as the major focus and priority of this chronic care guideline.

I. Effective Home Management: "...begins with self-management capability and this is defined as follows:

Self-management involves [the individual experiencing chronic illness] engaging in activities that protect and promote health, monitoring and managing of symptoms and signs of illness, managing the impacts of illness on functioning, emotions and interpersonal relationships and adhering to treatment regimens." (*Thorne 2006 [S]*)

"Based on our 25 years experience, review of the literature and a recent report from the Robert Wood Johnson meeting on self-management, there are five core self-management skills: problem solving, decision making, resource utilization, patient/healthcare provider relationship and taking action." (*Lorig 2003 [S]*)

II. Communication/Collaboration: Collaboration in health care can be defined as the process of "multidisciplinary interactions that facilitate common, positive patient care outcomes" (*Reimanis 2001 [S]*).

Principles of collaboration in health care include: understanding of patients' beliefs, wishes and circumstances; understanding of family beliefs and needs; identification of a single person to be the main link with each patient; collaborative definition of problems and goals; negotiated agreed upon plans and goals regularly reviewed; active follow up with patients and regular team review (*Wagner 1996 [S]*).

"A vital element in effective communication within the chronic illness context is the healthcare provider's recognition of the limits of science in solving the everyday problems that chronic illness entails. Thus, health promotion communications in chronic illness care are those that reflect respect for the patient's inherent expertise in matters pertaining to ...actually *living* with a chronic disease." (*Stille 2005 [S]*)

III. Care Coordination: Components of care coordination in a disease management program include population identification process; risk identification and matching of interventions with need; evidence-based practice guidelines; collaborative practice model; patient self-management education; outcomes management; routine reporting/feedback; and information technology (*Von Korff 1997 [S]*).

The essence of health care coordination is described as the availability of information of prior problems and services and its relevance to current care; information made available through easily accessible medical records; written and verbal communication among healthcare providers, patients, families and community resources and healthcare provider's knowledge gained from past experiences with patients (*Weingarten 2002 [M]*).

IV. Effective Provider Management: Common elements of effective chronic illness management include collaboration between service providers and patients; a personalized written care plan; tailored education in self-management; planned follow up; monitoring of outcomes and adherence to treatment; targeted use of specialist consultation of referral and protocols for stepped care.

Healthcare provider interventions in chronic disease management were identified in a meta-analysis of published reports as provider education; provider feedback; provider reminders; patient education and patient financial incentives. Health system requirements for effective chronic care includes ready access to appropriate systems of self-management supports that are evidence-based; adequately resourced with healthcare providers who are adequately trained, culturally sensitive to the patient's needs and who support the belief in the person's ability to learn self-management skills (*Tsai 2005 [M]*).

Appendix 6: Initial list of Clinical Questions and Outcomes of Interest Used to Guide Search and Selection of Evidence**First Priority Questions: PROGRAM DESIGN**

- 1) Do children with chronic illness who participate in self care management education programs (are there specific education models to be evaluated?) at an early age demonstrate fewer unplanned hospitalizations and improved functional abilities versus children who engage in programs in late adolescence?
- 2) Is clinician assessment versus parent report more effective in engaging children with chronic illness in learning self care management strategies?
- 3) In children with chronic illnesses, at what age is parental supervision of medical regimens effectively decreased such that children/teens are doing more self-management?
- 4) In children and their parents experiencing chronic illness, what intervention by clinicians produces self efficacy in home management?
- 5) What clinical practices promote self efficacy in children with chronic illness?
- 6) What interactional interventions by clinicians produce measurable improvements in self efficacy in parents whose children have chronic illness?
- 7) In children and parents experiencing chronic illness, what educational, motivational and behavioral interventions most effectively improve outcomes?
- 8) In children and adolescents with chronic disease, does the implementation of a self-management program improve clinical outcomes?
- 9) What are the evidence-based strategies for improved implementation of self-management programs in a hospital or ambulatory setting for families with chronic disease?
- 10) What are the evidence-based strategies for self-management programs for developmental stages of children with chronic illness?
- 11) What are the most effective clinician tools and interventions to promote or increase patient self-management skills?
- 12) What is the relationship between disease-related self efficacy and disease outcome?
- 13) In children with chronic illness, what clinical interventions (self-management education and support versus routine clinical office visit) improve HRQOL measures?" Long-term outcome would be: adult role satisfaction and mastery.

Second Priority Questions: TREATMENT APPROACHES

- 1) Among children with chronic illnesses, does provision of written treatment plans versus orally provided plans affect the family's knowledge of their regimen?
- 2) In patients with chronic disease, what is the effectiveness of clinician-delivered versus patient/peer-delivered self-management support in promoting improved outcomes?
- 3) In patients/parents who have children with a chronic disease, what impact does group size (small group versus large group) have on the delivery and outcomes of self-management programs?
- 4) In children and adolescents with chronic disease, what is the effectiveness of clinician-delivered self-management support in promoting improved outcomes?

Third Priority Question: MEASUREMENT

What is the best method to measure successful self-management in children and adolescents with chronic illness AND parents who have children with a chronic illness?

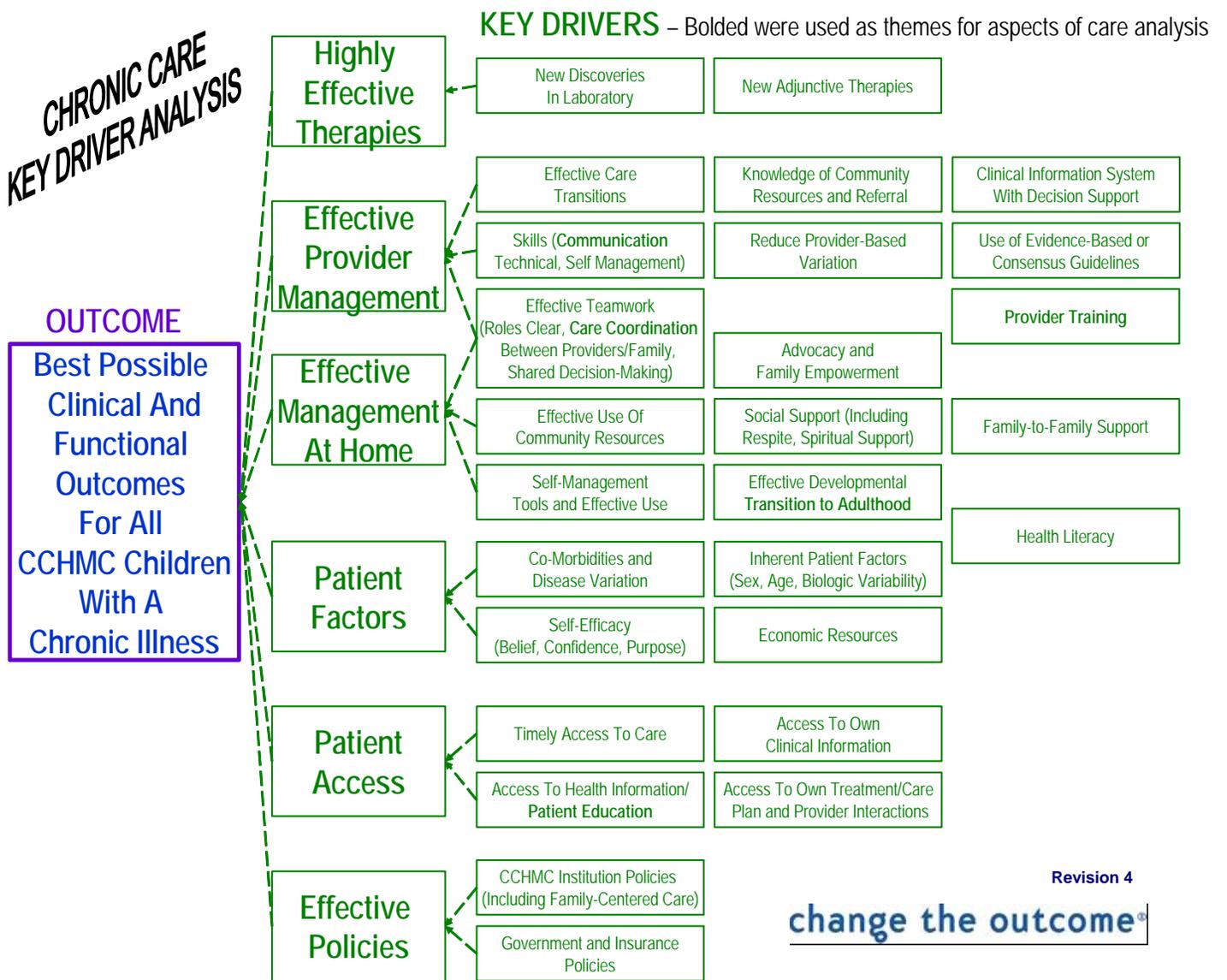
Fourth Priority Questions: SHARED DECISION MAKING,

- 1) In families of children with chronic illness faced with tough decisions does the use of a decision aid improve compliance with treatment regimes?
- 2) Among healthcare providers that use principles of shared decision making do families of children with chronic illness express more satisfaction with their health care versus those who do not?
- 3) In children with chronic conditions, does problem solving with a healthcare provider around adherence issues versus standard care improve adherence to the medical regimen or comfort with disease management?

Outcomes of Interest

- Clinical outcomes – symptom management (i.e. pain/comfort)
- Functional measures of ability
- Quality of life/health related quality of life
- Unplanned hospitalizations
- School: absences, participation, performance
- Adherence
- Patient/family satisfaction

Appendix 7: Chronic Care Improvement Key Drivers



Appendix 8: Additional Resources, Training Models, and Programs

<http://patienteducation.stanford.edu/programs>

<http://patienteducation.stanford.edu/organ/cdsites.html>

<http://patienteducation.stanford.edu/internet>

http://patienteducation.stanford.edu/programs_spanish

<http://www.ihl.org/ihl>

<http://som.flinders.edu.au/FUSA/CCTU/Annual%20Workshop.htm>

<https://www.racgp.org.au/Content/NavigationMenu/ClinicalResources/RACGPGuidelines/SharingHealthCare/>

<http://www.chcf.org/documents/chronicdisease/HelpingPatientsManageTheirChronicConditions.pdf>

<http://www.ext.vt.edu/pubs/family/350-052/350-052.html>

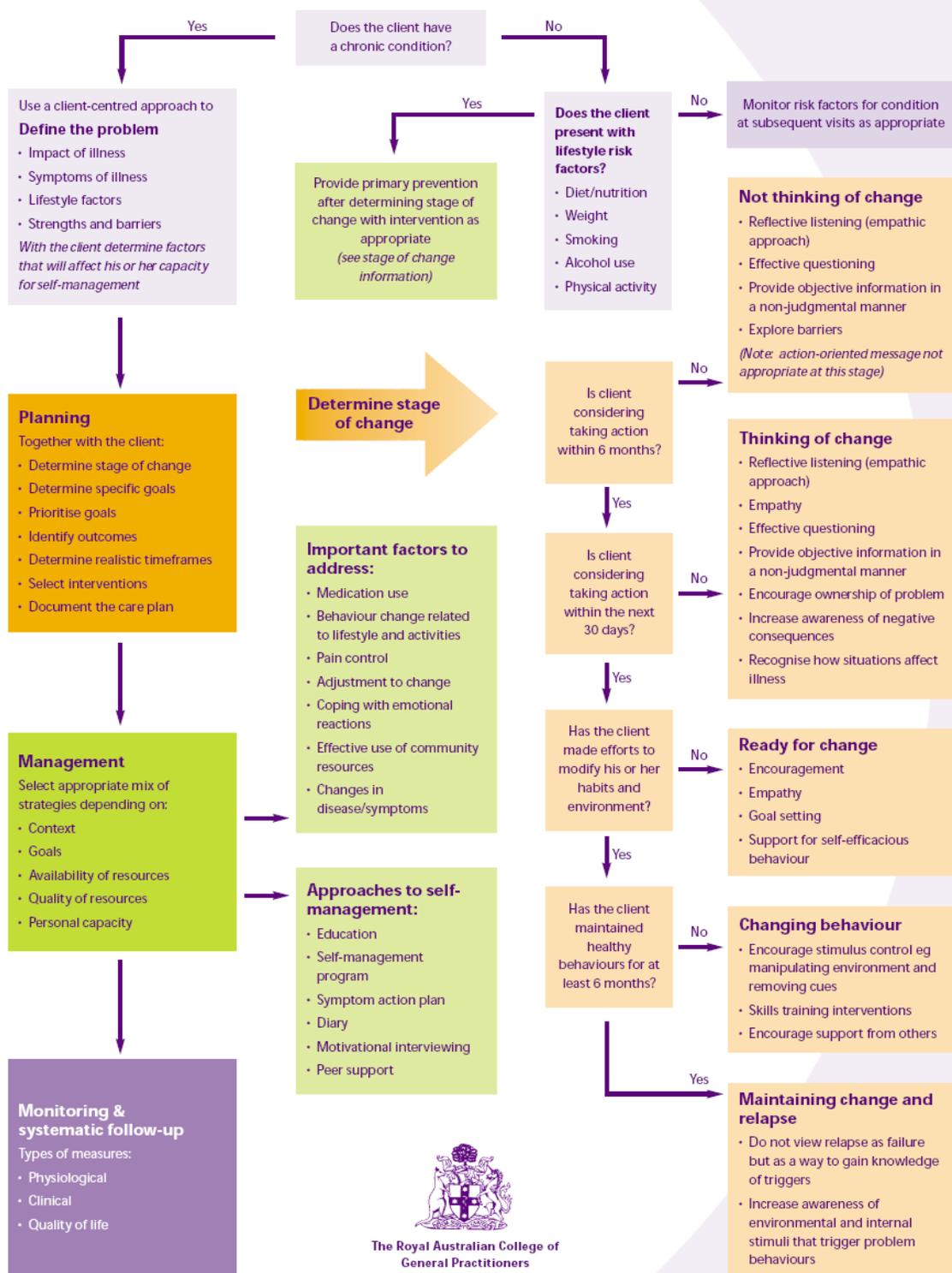
<http://www.motivationalinterview.org>

www.motivatehealthyhabits.com

Appendix 9: Sample Algorithm for Initiating Self-management

Sharing Health Care: Chronic Condition Self-Management Guidelines

Desktop guide for Nurses and Allied Health Professionals



Developed by the Royal Australian College of General Practitioners. Funded by Commonwealth Department of Health and Ageing

Used with permission: Courtesy of The Royal Australian College of General Practitioners

<https://www.racgp.org.au/Content/NavigationMenu/ClinicalResources/RACGPGuidelines/SharingHealthCare/>

Appendix 10: Samples of Assessment Tools

Condition	Parameter(s) Assessed by the Tool	Citation
Arthritis	Self efficacy (with children and with parents)	(Barlow 2001 [D], Barlow 2000 [D])
Asthma	Self-management scales: parent barriers, child/parent self efficacy; parent belief in treatment efficacy	(Bursch 1999 [O])
Asthma – QOL	PAQLQ: Pediatric Asthma Quality of Life Questionnaires: Age Range and Respondent 12 to 17 years, Child; # of items = 23	(Juniper 1996b [O], Juniper 1996a [O]) http://www.outcomes-trust.org/instruments.htm
	About My Asthma; Age range and Respondent 6 to 12 years, Child; # of items = 55	(Mishoe 1998 [O])
	Adolescent Asthma Quality of Life Questionnaire (AAQOL): Age Range and Respondent 12 to 17 years, Child; # of items = 32	(Rutishauser 2001 [O])
Adolescent health	CHIP-AE: Child Health and Illness Profile — Adolescent Edition (Note: has 150 items, implementation may be challenging)	http://www.outcomes-trust.org/instruments.htm
	Quality of Life Profile – Adolescent Version (QOLP-AV); Age Range and Respondent 14 to 20 years, Child; # of items = 54	(Raphael 1996 [O])
Child health	CHQ: Child Health Questionnaire (parent, child, adolescent versions) PedsQL: (parent, child, adolescent versions)	http://www.outcomes-trust.org/instruments.htm
	Psychosocial Assessment Tool (PAT)	(Kazak 2001 [O])
Cancer	The Pediatric Cancer Quality of Life Inventory Age Range and Respondent 8 to 18 years, Child and Parent; # of items = 32	(Varni 1998 [O])
Cystic Fibrosis	CFQ-Revised: 44 item teen-adult measure (14 years and older), 35-item measure for children 6 to 13 years and parent-proxy version to assess the effects of new therapies, to document the progression of disease, and to inform clinical practice.	(Modi 2006 [O], Quittner 2005 [O])
	Cystic Fibrosis Quality of Life Questionnaire Age Range and Respondent 14 years to adult, patient, # of items = 52	(Gee 2000 [O])
	Self-efficacy expectations assessment (Parent’s of CF children)	(Bartholomew 1993 [O])
	Self-Care Independence Scale (SCIS)	(Patton 2003 [O])
Decision making	Decision aid tools for various health decisions/conditions	(O’Connor 2003 [M]) http://decisionaid.ohri.ca/AZinvent.php
	Center for Shared Decision Making offers some Pediatric specific decision aids in their child health category	http://www.dhmc.org/webpage.cfm?site_id=2&org_id=108&morg_id=0&sec_id=0&gsec_id=39685&item_id=39685
	A generic decision aid	http://decisionaid.ohri.ca/decguide.html
Depression	PHQ-9: Self administered questionnaire for depression severity over time	http://depression-Primarycare.org/clinicians/toolkits
Diabetes	Diabetes Quality of Life Measure: Age Range and Respondent 13 years to adult, patient, # of items = 46	(DCCT 1988 [O])
Epilepsy	Impact of Pediatric Epilepsy Scale: Age Range and Respondent 2 to 18 years, Parent, # of items = 11	(Camfield 2001 [O])
	Quality of Life in Childhood Epilepsy: Age Range and Respondent 4 to 18 years, Parent, # of items = 73	(Sabaz 2000 [O])
	Seizure Self-Efficacy Scale for Children (SSES-C)	(Caplin 2002 [O])
General health – all ages	Web-based general health assessment with depth built in; provides self-management assistance	(Wasson 2006 [C], Wasson 2006 [O]) http://www.howsyourhealth.org/
	The Child Quality of Life Questionnaire (CQOL): Age Range and Respondent 9 to 15 years, Child and/or Parent, # of items = 15	(Graham 1997 [O])
Patient activation 	The Patient Activation Measure (PAM), a 22-item measure that assesses patient knowledge, skill, and confidence for self-management	(Hibbard 2005 [O], Hibbard 2004 [O]) http://darkwing.uoregon.edu/%7Ejhibbard/licenseinfo.htm
Spina bifida	Quality of Life in Spina Bifida Questionnaire: Age Range and Respondent 5 to 12, Parent or 13 to 20 years, patient, # of items = 44	(Parkin 1997 [O])

Appendix 11: Criteria to Assess the Validity of an Assessment Tool

CRITERION	DETAILS		
RELIABILITY concerned with questions of stability and consistency (i.e. does the same measurement tool yield stable and consistent results when repeated over time?)	Inter-rater Internal consistency ^b	Test-retest reliability Reliability across cultures	Reliability of administrative records
VALIDITY ^c refers to the extent the tool actually measures what it is intended to measure	Face and content validity ^d Convergent validity ^e	Concurrent validity ^f Predictive validity ^g	

^b Where multiple-item scales are available, it is possible to assess whether the individual items measuring the concept of interest are systematically related to each other and to the overall scale score. Higher inter-item correlations show a greater degree of internal consistency. The industry standard statistical measure for assessing internal consistency is Cronbach’s alpha. Alpha scores of 0.80 show good levels of internal consistency.

^c The assessment of validity is not a single process. Its major purpose is to determine the level to which an instrument is able to measure the construct of interest. The construct of interest relative to a comprehensive assessment in continuing care is the overall level and type of care need across a multidimensional array of possibilities.

^d The most common approach to assessing validity is a simplistic method of seeking agreement from interested parties that the instrument appears valid. While this is probably a necessary condition for validity, it is not sufficient evidence to establish validity. However, any instrument must achieve at least face validity before continuing on to establish the more stringent forms of validity.

Content validity refers to the extent to which the instrument covers the relevant concepts in the areas being evaluated. For example, in continuing care, it may be important for any assessment instrument to cover the major domains of functional ability and the various psychological, physical, social and environmental components and determinants of health and well being. Within these domains, assessment of social support may need to consider instrumental and emotional support, availability of caregivers, living arrangements, caregiver strain, capacity to deal with increasing care giving demands, and access to formal services. Content validity is typically addressed by consultation with researcher, service providers, policymakers and consumers.

^e This method assesses the extent to which associations between concepts of interest reflect expected patterns based on the available literature. An example of this type of validity assessment would be to compare behavior patterns with mental status with the expectation that those persons with greater cognitive impairment demonstrate greater levels of behavior disturbance. Hence, this method determines whether concepts that are considered to be related to each other are shown to be related to each other in the data yielded by the assessment instrument.

^f Determining the level to which a “new assessment” instrument is able to act as a substitute for a “gold standard” (criterion) measure. This is important for a number of reasons:

1. It assists in answering the question “to what degree does the instrument measure what you think it measures?”
2. If an assessment instrument approximates a criterion measure then it can replace the use of a more time-consuming criterion measure without significant loss of generality.
3. With the approximation (new assessment) and the criterion (gold standard) measures available they may be used to assess the ability of the “new assessment” to detect all true cases (sensitivity) and its ability to detect only true cases (specificity).

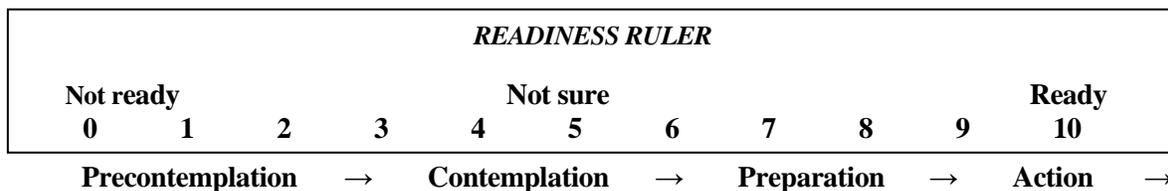
^g In developing assessment instruments that aim to measure risks of adverse outcomes it is important to evaluate the capacity of the instrument to predict the future occurrence of events of interest (e.g. hospitalization, falls, mortality). This inherently requires longitudinal data and relatively complex statistical analyses, making publications in this area relatively rare. Nonetheless, this concept forms part of the foundation for why assessment is done in the first place. If an instrument gives us the opportunity to look ahead with some degree of certainty, it allows for the avoidance of unnecessary suffering. It makes service provision more effective and it allows for the allocation of resources in a way that appropriately reflects need and expected outcomes.

General Guidelines for Interpreting Reliability Coefficients	
Reliability coefficient value	Interpretation
0.90 and up	excellent
0.80 to 0.89	good
0.70 to 0.79	adequate
below 0.70	may have limited applicability

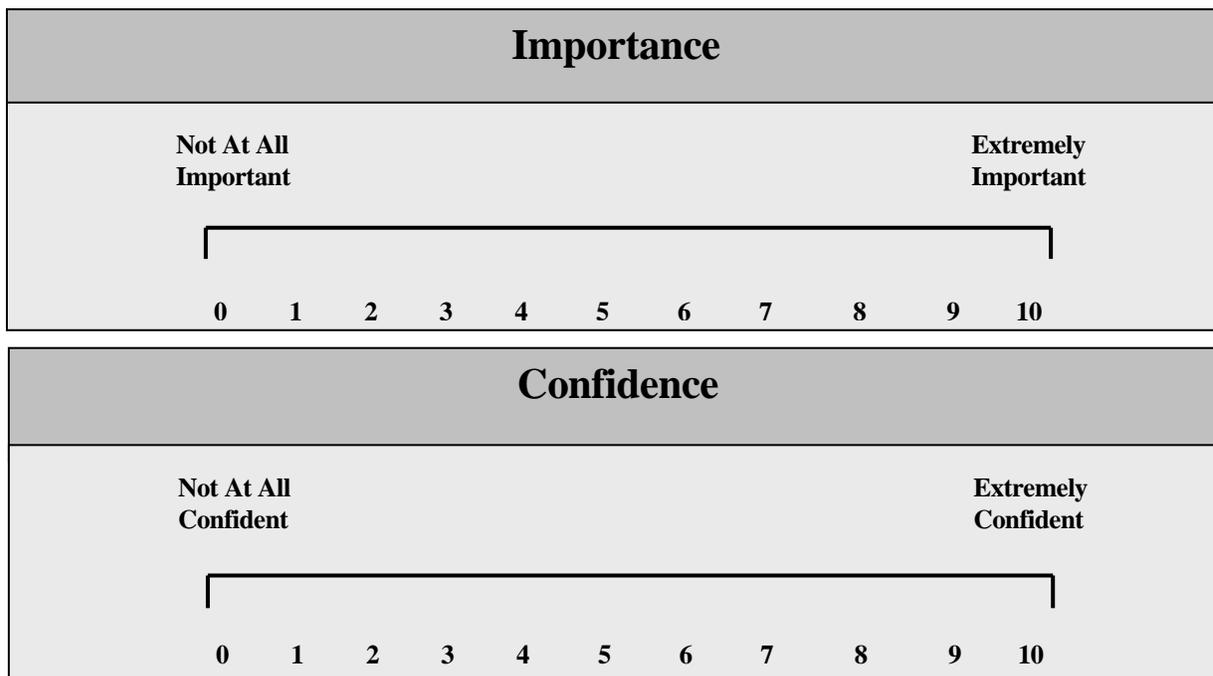
General Guidelines for Interpreting Validity Coefficients	
Validity coefficient value	Interpretation
above 0.35	very beneficial
0.21 to 0.35	likely to be useful
0.11 to 0.20	depends on circumstances
below 0.11	unlikely to be useful

Appendix 12: Measure of Readiness, Importance and Confidence

Also refer to Guideline recommendation #6



The lower numbers represent less readiness to change (*Precontemplation*) and higher numbers represent greater readiness to change (*Action*). Persons can move forward and backward along the continuum of readiness to change. Numerical assessments are not fixed, nor are they always linear. The patient/family can move forward or backward across stages or jumps from one part of the continuum to another, in either direction and at various times. The healthcare provider’s role is to facilitate movement in a positive direction. As patients/families continue in treatment, healthcare providers can use the ruler periodically to monitor how motivation changes as treatment progresses.

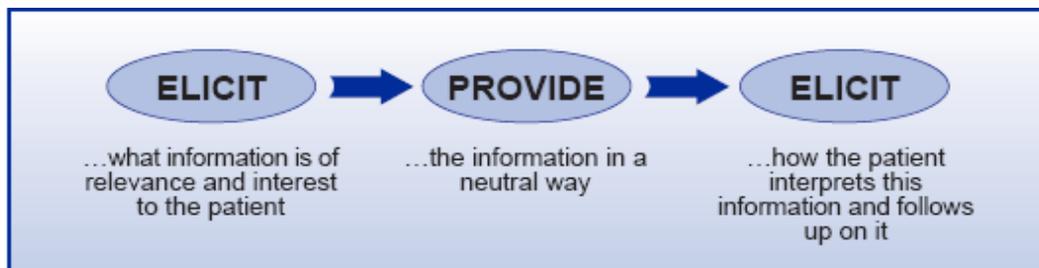


Confidence can be measured on a scale from 0 (*not at all confident*) to 10 (*extremely confident*). A score of 7 or above indicates the patient’s/family’s likelihood of achieving a given self-management goal. If the score is less than 7, then it is important to problem solve (choose a more easily achieved goal), alter the plan to fit realistic expectations, and build self efficacy to avoid failure (*Lorig 2003 [SJ]*).

Example of possible dialogue for addressing importance and confidence: Adaptation of a tool by (*Miller 2002 [E]*).

1. “On a scale of 0 to 10, with 0 being not at all important to *begin dieting* (*may substitute the desired behavior*) and 10 being extremely important to begin, what number would you give yourself at this time?”
2. “If you were to decide to *begin dieting* now, how confident are you that you would succeed?
On a scale of 0 to 10, with 0 being not at all confident and 10 being extremely confident, how confident are you that you could change your eating habits?”
3. “Tell me why you are at 4 (*use chosen score*) and not a 10?” encourages change talk, rather than resistance where the person must defend his/her current behavior or position.
4. Listen carefully at this point as one will begin to identify strengths on which to build and possible motivating factors that might influence behavior change.
5. “What would need to happen for you to go from a (*chosen number*) to a (*higher number*)?”
6. “How can we help you to go from a (*chosen number*) to a (*higher number*)?”

Appendix 13: Elicit – Provide – Elicit Method Figure and tables used with permission (*Mash 2004 [O]*).



Three-step process of exchanging information between healthcare provider and patient/family:

Step one: Elicit – Ask the patient or family what he/she/they already know about the topic on the visit agenda (the health behavior).

Step two: Provide – Ask the patient’s/family’s permission to provide information, give an opinion, direction or concerns about behavior in a neutral and nonjudgmental manner.

Step three: Elicit – Ask for the patient’s/family member’s thoughts about the information that has been provided (*Miller 2006 [E]*).

Table I: The spirit underlying motivational interviewing (adapted from Miller and Rollnick):

Collaboration	The relationship between the patient/family and the health worker is a partnership. The patient’s/family’s point of view is valued and key decisions are negotiated. The health worker aims to generate a climate that is suitable for change.
Evocation	The knowledge, motivations and skills for change are believed to be within the patient/family. The health worker’s approach to consultations is quiet and eliciting in order to draw out the patient’s own views and values. Coercive and confrontational approaches tend to be counterproductive.
Autonomy	The patient’s/family’s right and ability to make independent and informed decisions are encouraged. The health worker comes alongside the patient to play a supportive role, rather than to dictate what the patient/family should do.

Table II: Summary of group meetings by Stages of Readiness to Change and Brief Motivational Interviewing (BMI)skills:

Session	Stage of Readiness	BMI Task	Key BMI Skills
1	Introduction/assessing readiness to change with readiness ruler	<ul style="list-style-type: none"> Negotiate where to start Explore importance, stage of readiness 	<ul style="list-style-type: none"> Set the agenda Open-ended questions Scaling questions
2	Pre-contemplation	<ul style="list-style-type: none"> Exchange information carefully Minimize resistance Instill hope Support personal choice 	<ul style="list-style-type: none"> Elicit-provide-elicited Emphasize personal choice and control Personalize risk factors
3	Contemplation	<ul style="list-style-type: none"> Facilitate navigation of ambivalence Values clarification 	<ul style="list-style-type: none"> Open-ended questions Scaling questions Examine pros and cons
4	Ready to change (preparation and action)	<ul style="list-style-type: none"> Help set goals and targets Build confidence Focus on practical aspects Identify difficult situations; anticipate challenges Identify supportive relationships 	<ul style="list-style-type: none"> Decision balance sheet Brainstorm solutions Help to learn from own and others’ past successes and failures Collaborative goal setting
5	Relapse	<ul style="list-style-type: none"> Avoid recrimination Reassure that relapse is common; more attempts to change associated with successful change Re-assess readiness 	<ul style="list-style-type: none"> Take the opportunity to learn from the experience Help learn cues that trigger old behavior Assist in creation of new change plan if ready

Appendix 14: Self-Management Personal Action Plan (an example of a “5A – Agree” tool)



MY PERSONAL ACTION PLAN _____ (Patient’s Name)

1. Something I want to change (health or personal goal) _____

2. How important is it to me to make this change in my health? (circle one)

0 1 2 3 4 5 6 7 8 9 10

Not at all important ↔ Extremely important

3. Description of what it is I want to do:

What _____

How _____

When and how often _____

With whom _____

4. What might make it hard for me to achieve my goal (barriers)?

5. What can I do to overcome these barriers?

6. How confident am I that I can meet my goal?

0 1 2 3 4 5 6 7 8 9 10

Not at all confident ↔ Very confident

7. Some help or information I might need in accomplishing my goal is:

8. I will know my plan is working when _____

I agree to this plan of action and will review my plan and progress with _____ on _____ by email _____ or phone _____ or text message _____

(Participant’s Signature)

(Date)

(Facilitator’s Signature)

(Date)



Appendix 15: Developmental Stages and Milestones and Possible Self-Management Tasks

(page 1 of 2)

Adapted from: PACI Self-Management Support Treatment Manual, Pediatric Asthma Care Study; Lozano Paula; MD, MHP; Schmalig Karen, PhD

Age (approximate)	Piaget Cognitive Development	Erikson Psychosocial Development	Kohlberg Moral Development	Possible Self-Management Support
Birth to 18 months	<u>Sensorimotor</u> Infant progresses through several stages. Starts with simple reflexes; begins to notice one can have an effect on environment; behaviors cause repeat actions; thoughts are confined to actions; actions over time become intentional, purposeful, and goal-directed; gradually begins exploration and discovery; imitation is accurate; begins to comprehend and can differentiate between the symbol and what is real.	<u>Trust versus Mistrust</u> Trust develops when needs are consistently met by loving and caring person. Mistrust develops when needs are not met and develops suspicion and withdrawal. With trust, develops a sense of hope, tolerates frustration; can delay gratification.	<u>“Amoral”</u> Moral reasoning cannot begin until child reaches certain level of cognitive development..	Self-management support directed to parents
18 months to 3 years	<u>Preoperational: Preconceptual</u> Uses symbolic thought to recall the past, consider the present, and anticipate the future; magical thinking predominates.	<u>Autonomy versus Shame and Doubt</u> Autonomy develops as child gains increasing control of body and control of environment; shame and doubt develop when forced to be dependent in areas in which one has capability of control. Positive outcome with sense of self control and self esteem.	<u>Preconventional: Obedience and Punishment</u> Makes decisions on basis of fear of punishment; good and bad are defined based on physical consequences.	<ul style="list-style-type: none"> • Continue to primarily address parents • Support learning body awareness and parts as well as verbal labels for symptoms • Support knowing routines and what is expected • Allow some choices (i.e.; order of exercises, or choice between <i>specified</i> treats or rewards)
3 to 6 years	<u>Preoperational: Intuitive</u> Increased use of symbolic representation and imagination to come up with new and creative ways of doing things; magical world starts being replaced by reality as experience grows.	<u>Initiative versus Guilt</u> Uses sense of power to explore physical world; imagines fantasy world; conscience is developed; begins to respond to inner voice. Guilt occurs when one takes on activities in conflict with goals of others. Positive outcome seen in accomplishments and purpose.	<u>Preconventional: Instrumental Relativist Orientation</u> Makes decisions on what one desires; very egocentric; may do something intermittently to please others if there is an advantage to oneself ↓ continues through next stage (next page)	<ul style="list-style-type: none"> • Continue to primarily address parents • Use games to help with decision making • Use reward systems such as star charts • Give child simple explanations (i.e.; “this medicine will...”)

Appendix 15: Developmental Stages and Milestones and Possible Self-Management Tasks

Adapted from: PACI Self-Management Support Treatment Manual, Pediatric Asthma Care Study, Lozano Paula, MD, MHP, Schmalting Karen, PhD

Age (approximate)	Piaget Cognitive Development	Erikson Psychosocial Development	Kohlberg Moral Development	Possible Self-Management Support
6 to 11 years	<p><u>Concrete Operational</u> Thought becomes increasingly logical and coherent; able to explore dimensions of a problem; understands changes and can reverse changes to the world mentally to gain understanding; can reason using stable rule system; understands some patterns.</p>	<p><u>Industry versus Inferiority</u> Child works to complete activities/tasks to achieve sense of accomplishment and mastery; learns rules; works cooperatively and competitively. Inferiority occurs when too much is expected. Positive outcome occurs with sense of competence.</p>	<p><u>Conventional: Interpersonal Concordance Orientation</u> Behavioral decisions based on desire to gain approval from others; judgments based on intentions.</p> <p><u>Conventional: Law and Order Orientation</u> Behavioral decisions based on laws and respect for authority; laws take precedence over personal wishes.</p>	<ul style="list-style-type: none"> • Children able to report and recognize symptoms • Demonstrate “listening to self” (internal stethoscope) • Demonstrate exercises • Take medicine when reminded; eventually without reminders • Begin to address child more directly in discussion of care plan • Child keeps a copy of care plan • Use reward system such as star charts or activities • Use of stories to stimulate problem solving • Role play to rehearse new skills in life-like situations
12 to 18 years	<p><u>Formal Operational</u> Thought becomes adaptable and flexible; can deal with complex problems of reasoning; can think abstractly; confronts problems in terms of what is possible; uses complex deductive reasoning.</p>	<p><u>Identity versus Role Confusion</u> Child pre-occupied with physical appearance; self perception is viewed through peers and society. Role confusion occurs when unable to resolve conflicts between concept of self and others and society. Positive outcome occurs with loyalty to values and other people.</p>	<p><u>Postconventional: Social Contract Legalistic</u> Morality based on personal views; works to change laws that are not moral or just</p> <p><u>Postconventional: Universal Ethical Principle</u> Morality based on internal ideals and conscience instead of social rules; universal principles of what is just.</p>	<ul style="list-style-type: none"> • Long term goal would be for child to prepare and take meds independently. <i>Note: withdrawal of parental support/supervision is a gradual and individualized process, however, parental support in chronic care is associated with improved outcomes.</i> • Demonstrate good preparation and judgment by making arrangements for meds to be taken when away from home • Keep written records of meds and care plan and symptoms—will initially need guidance • Discuss plan with teenager directly • Keep the regimen as simple as possible • Anticipate possible side effects that may be bothersome to teen • Ask teen to identify obstacles up front and plan to address • Model new behaviors • Contract may be beneficial; role play occasionally helpful

Members of Chronic Care: Self-Management Guideline Team 2007

Co-Chairs

Janalee Taylor, RN, MSN, CNS, Advanced Practice Nurses
Anita Schambach, RN, MS, BCIAC, Integrative Care

Maria Britto, MD, MPH, Div. of Adolescent Medicine
Karen Burkett, RN, MSN, CNP, Ctr. For Professional Excel & Rsch/EBP
Tammy Dimuzio, RN, MS, CDE, A3S Outpatient Diabetes/Endo/CRC
Wendy Gerhardt, RN, MSN, Patient Services
Susmita Kashikar-Zuck, PhD, Behavioral Med & Clinical Psychology
Avani Modi, PhD, Behavioral Med & Clinical Psychology
Dawn Nebrig, LISW, MSW, Clinical Development & Education
Dave Pruitt, MD, Div. of Physical Medicine & Rehabilitation
Judy Ragsdale, M.Div, ACPE, Clinical Pastoral Education
Heather Rolke, RN, BSN, A6 Inpatient Unit - Adolescent
Thomas Webb, MD, Div of Development & Behavioral Pediatrics
Jeanne Weiland, RN, MSN, CNS, Advanced Practice Nurses

Division of Health Policy & Clinical Effectiveness Support

Eduardo Mendez, RN, MPH, Dir. Evidence-Based Care, Facilitator
Edward Donovan, MD, Medical Dir., Clin. Effect, Methodologist
Danette Stanko-Lopp, MA, MPH, Epidemiologist
Carol Tierney, RN, MSN, Education Coordinator
Eloise Clark, MPH, MBA, Guideline Program Administrator
Darrin Hooks, Administrative Assistant

All Team Members and Clinical Effectiveness support staff listed above have signed a conflict of interest declaration.

Ad hoc Advisors

Barbarie Hill, MA, AHIP, Manager, Pratt Library
Cheryl Hoying, RN, PhD, Sr. V.P., Patient Services
Uma Kotagal, MBBS, MSc, Sr. V.P., Quality and Transformation
Laura Werts, BS, CMP, CME Coordinator

Development Process

The process by which this guideline was developed is documented in the [Guideline Development Process Manual](#); a Team Binder maintains minutes and other relevant development materials. The recommendations contained in this guideline were formulated by an interdisciplinary working group which performed systematic and critical literature reviews, using the grading scale that follows, and examined current local clinical practices.

Guideline focus was based on family and healthcare provider feedback using consensus techniques. See methods in development process section below and related [Appendices 4, 5, 6, and 7](#). Self-management (effective management at home) emerged as the priority topic for this guideline.

The following processes and techniques were used to provide focus, direct guideline development and prioritize domains of the Chronic Care Model:

- *Delphi Method*  used with chronic care quality improvement team leaders (nurses, physicians, social workers), parents serving on chronic care quality improvement teams, guideline Team members, and the Family Advisory Council.

CCHMC Evidence Grading Scale			
M	Meta-analysis or Systematic Review	O	Other evidence
A	Randomized controlled trial: large sample	S	Review article
B	Randomized controlled trial: small sample	E	Expert opinion or consensus
C	Prospective trial or large case series	F	Basic Laboratory Research
D	Retrospective analysis	Q	Decision analysis

- *Nominal Group Technique*  was used with guideline Team members.
- Surveys were completed with families of children and patients experiencing various chronic illnesses.
- A *Chronic Care Key Driver Analysis* was developed with local chronic care expert groups and quality improvement consultants to identify critical components of the chronic care management process, needs and experience. See [Appendix 7](#).

Delphi Method and Nominal Group Technique were employed to achieve consensus for a specific focus area. Delphi Method was accomplished by respondents through computer-based surveys. Several cycles of surveys were completed. Survey responses regarding aspects of care were categorized by theme based on the Chronic Care Key Driver Analysis. Aspects of care were categorized by them independently by the Guideline co-chairs and consensus was achieved. Nominal Group Technique was then used to obtain priority rankings in order to determine the domain of focus of the Chronic Care Model. See [Appendix 4](#) and [Appendix 5](#).

Note: Initial clinical questions were categorized into 4 major groups (see [Appendix 6](#)) followed by Nominal Group Technique (NGT) that was used by the Team to prioritize the 4 groups of questions, such that the group with the highest NGT score was the first priority for searching/evaluating evidence followed by the group with the next highest score, etc. We concluded that Team members found it challenging to distinguish the questions in Group #4 and #3, thus their NGT scores were very similar. Groups #2 and #1 were seen as lower priorities for this Guideline, though the Team concluded it would try to work on that evidence for inclusion in this Guideline as time allows. The following prioritized topical categories for questions generated by Team members were pursued: First (NGT score = 39): PROGRAM DESIGN ; Second (NGT score = 38): TREATMENT APPROACHES; Third (NGT score = 30): MEASUREMENT; Fourth (NGT score = 23): SHARED DECISION MAKING.

To select evidence for critical appraisal by the group for the development of this guideline, the Medline, EmBase and the Cochrane databases were searched for dates of January 1970 to June 2006 to generate an unrefined, "combined evidence" database using a search strategy focused on answering clinical questions relevant to Chronic Care Self-Management. A few focused searches were done in late 2006 that additionally included searching the PsychInfo database.

Searches employed a combination of Boolean searching on human-indexed thesaurus terms (MeSH headings using an OVID Medline interface) and "natural language" searching on searching on human-indexed thesaurus terms (MeSH headings using an OVID Medline interface) and "natural language" searching on words in the title, abstract, and indexing terms. The citations were reduced by: eliminating duplicates, review articles, non-English articles, and adult

articles. The resulting abstracts were reviewed by a methodologist to eliminate low quality and irrelevant citations. During the course of the guideline development, additional clinical questions were generated and subjected to the search process, and some relevant review articles were identified.

Potential Quality Measures which may be monitored include:

- Self efficacy
- Health-related quality of life
- Healthcare utilization (hospital days, unscheduled visits, etc.)
- Parent/patient satisfaction
- Missed days from usual activities
- Cost
- Knowledge
- Health behaviors
- Specific disease measures (i.e. pain, peak flow, HbA1c, etc.)

Once the guideline is in place, the development Team will reconvene periodically (no less than every three years) to explore the continued validity of the guideline. This phase can be initiated at any point that evidence indicates a critical change is needed.

Recommendations have been formulated by a consensus process directed by best evidence, patient and family preference and clinical expertise. During formulation of these recommendations, the Team members have remained cognizant of controversies and disagreements over the management of these patients. They have tried to resolve controversial issues by consensus where possible and, when not possible, to offer optional approaches to care in the form of information that includes best supporting evidence of efficacy for alternative choices.

The guideline has been reviewed and approved by clinical experts not involved in the development process, senior management, other appropriate hospital committees, and other individuals as appropriate to their intended purposes.

The guideline was developed without external funding. All Team Members and Clinical Effectiveness support staff listed have declared whether they have any conflict of interest and none were identified.

Copies of this Evidence-based Care Guideline (EBCG) and its companion documents are available online and may be distributed by any organization for the global purpose of improving child health outcomes. Website address: www.cincinnatichildrens.org/evidence

Examples of approved uses of the EBCG include the following:

- copies may be provided to anyone involved in the organization's process for developing and implementing evidence-based care guidelines;
- hyperlinks to the CCHMC website may be placed on the organization's website;
- the EBCG may be adopted or adapted for use within the organization, provided that CCHMC receives appropriate attribution on all written or electronic documents; and
- copies may be provided to patients and the clinicians who manage their care.

Notification of CCHMC at HPCEInfo@cchmc.org for any EBCG, or its companion documents, adopted, adapted, implemented or hyperlinked by the organization is appreciated.

NOTE: These recommendations result from review of literature and practices current at the time of their formulations. This guideline does not preclude using care modalities proven efficacious in studies published subsequent to the current version of this document. This document is not intended to impose

standards of care preventing selective variances from the recommendations to meet the specific and unique requirements of individual patients. Adherence to these recommendations is voluntary. The physician in light of the individual circumstances presented by the patient must make the ultimate judgment regarding the priority of any specific procedure.

For more information about this guideline, its supporting evidence and the guideline development process, contact the Health Policy & Clinical Effectiveness office at: 513-636-2501 or HPCEInfo@cchmc.org.

24. **Deakin, T.; McShane, C. E.; Cade, J. E.; and Williams, R. D.:** Group based training for self-management strategies in people with type 2 diabetes mellitus. *Cochrane Database Syst Rev*, (2): CD003417, 2005, [M] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Deakin_2005.pdf
25. **Degotardi, P. J.; Klass, E. S.; Rosenberg, B. S.; Fox, D. G.; Gallelli, K. A.; and Gottlieb, B. S.:** Development and Evaluation of a Cognitive-Behavioral Intervention for Juvenile Fibromyalgia. *J Pediatr Psychol*, 2005, [C] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Degotardi_2005.pdf
26. **Denboba, D.; McPherson, M. G.; Kenney, M. K.; Strickland, B.; and Newacheck, P. W.:** Achieving family and provider partnerships for children with special health care needs. *Pediatrics*, 118(4): 1607-15, 2006, [O] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Denboba_2006.pdf
27. **Dorr, D. A.; Wilcox, A.; Burns, L.; Brunker, C. P.; Narus, S. P.; and Clayton, P. D.:** Implementing a multidisease chronic care model in primary care using people and technology. *Dis Manag*, 9(1): 1-15, 2006, [D] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Dorr_2006.pdf
28. **Drotar, D. et al.:** Recommendations to enhance comprehensive care for children with chronic health conditions and their families. *Children's Services: Social Policy, Research, & Practice*, 2001, [E] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Drotar_2001.pdf
29. **Dunn, C.; Deroo, L.; and Rivara, F. P.:** The use of brief interventions adapted from motivational interviewing across behavioral domains: a systematic review. *Addiction*, 96(12): 1725-42, 2001, [M] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Dunn-2001_SR_Motivational_Interviewing.pdf
30. **Eccleston, C.; Yorke, L.; Morley, S.; Williams, A. C.; and Mastroiannopoulou, K.:** Psychological therapies for the management of chronic and recurrent pain in children and adolescents. *Cochrane Database Syst Rev*, (1): CD003968, 2004, [M] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Eccleston_2004.doc
31. **Ellis, D. A.; Frey, M. A.; Naar-King, S.; Templin, T.; Cunningham, P.; and Cakan, N.:** Use of multisystemic therapy to improve regimen adherence among adolescents with type 1 diabetes in chronic poor metabolic control: a randomized controlled trial. *Diabetes Care*, 28(7): 1604-10, 2005, [B] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Ellis_2005.pdf
32. **Erickson, S. J.; Gerstle, M.; and Feldstein, S. W.:** Brief interventions and motivational interviewing with children, adolescents, and their parents in pediatric health care settings: a review. *Arch Pediatr Adolesc Med*, 159(12): 1173-80, 2005, [S] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Erickson_2005.pdf
33. **Evans, D.; Clark, N. M.; Feldman, C. H.; Rips, J.; Kaplan, D.; Levison, M. J.; Wasilewski, Y.; Levin, B.; and Mellins, R. B.:** A school health education program for children with asthma aged 8-11 years. *Health Education Quarterly*, 14(3): 267-79, 1987, [C] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Evans_1987.pdf
34. **Evans, D.; Clark, N. M.; Levison, M. J.; Levin, B.; and Mellins, R. B.:** Can children teach their parents about asthma? *Health Educ Behav*, 28(4): 500-11, 2001, [A] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Evans_2001.pdf
35. **Farmer, J. E.; Marien, W. E.; Clark, M. J.; Sherman, A.; and Selva, T. J.:** Primary care supports for children with chronic health conditions: identifying and predicting unmet family needs. *J Pediatr Psychol*, 29(5): 355-67, 2004, [O] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Farmer_2004.pdf
36. **Fireman, P.; Friday, G. A.; Gira, C.; Vierthaler, W. A.; and Michaels, L.:** Teaching self-management skills to asthmatic children and their parents in an ambulatory care setting. *Pediatrics*, 68(3): 341-8, 1981, [C] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Fireman_1981.pdf
37. **Flores, G.:** Culture and the patient-physician relationship: achieving cultural competency in health care. *J Pediatr*, 136(1): 14-23, 2000, [S] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Flores_2000.pdf
38. **Gance-Cleveland, B.:** Motivational interviewing as a strategy to increase families' adherence to treatment regimens. *J Spec Pediatr Nurs*, 10(3): 151-5, 2005, [S] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Gance_Cleveland_2005.pdf
39. **Gee, L.; Abbott, J.; Conway, S. P.; Etherington, C.; and Webb, A. K.:** Development of a disease specific health related quality of life measure for adults and adolescents with cystic fibrosis. *Thorax*, 55(11): 946-54, 2000, [O] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Gee_2000.pdf
40. **Gibson, P. G.; Powell, H.; Coughlan, J.; Wilson, A. J.; Abramson, M.; Haywood, P.; Bauman, A.; Hensley, M. J.; and Walters, E. H.:** Self-management education and regular practitioner review for adults with asthma. *Cochrane Database Syst Rev*, (1): CD001117, 2004, [M] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Gibson_2004.pdf
41. **Glasgow, R. E.; Funnell, M. M.; Bonomi, A. E.; Davis, C.; Beckham, V.; and Wagner, E. H.:** Self-management aspects of the improving chronic illness care breakthrough series: implementation with diabetes and heart failure teams. *Ann Behav Med*, 24(2): 80-7, 2002, [O] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Glasgow_2002.pdf
42. **Glasgow, R. E.; Goldstein, M. G.; Ockene, J. K.; and Pronk, N. P.:** Translating what we have learned into practice. Principles and hypotheses for interventions addressing multiple behaviors in primary care. *Am J Prev Med*, 27(2 Suppl): 88-101, 2004, [S] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Glasgow_2004_FiveAs.pdf
43. **Glasgow, R. E.; La Chance, P. A.; Toobert, D. J.; Brown, J.; Hampson, S. E.; and Riddle, M. C.:** Long-term effects and costs of brief behavioural dietary intervention for patients with diabetes delivered from the medical office. *Patient Educ Couns*, 32(3): 175-84, 1997, [A] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Glasgow_1997.pdf
44. **Graham, P., Stevenson, J., & Flynn D.:** A New Measure of Health-Related Quality of Life for Children. *Psychology and Health*, 12(5): 655-665, 1997, [O] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Graham_1997.pdf
45. **Greene, J.; Yedidia, M. J.; and The Take Care to Learn Evaluation, C.:** Provider behaviors contributing to patient self-management of chronic illness among underserved populations. *Journal of Health Care for the Poor & Underserved*, 16(4): 808-24, 2005, [C] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Greene_2005.pdf
46. **Haby, M. M.; Waters, E.; Robertson, C. F.; Gibson, P. G.; and Ducharme, F. M.:** Interventions for educating children who have attended the emergency room for asthma. *Cochrane Database Syst Rev*, (1): CD001290, 2004, [M] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Haby_M_2004.pdf

47. **Hauser, S. T.; Jacobson, A. M.; Lavori, P.; Wolfsdorf, J. I.; Herskowitz, R. D.; Milley, J. E.; Bliss, R.; Wertlieb, D.; and Stein, J.:** Adherence among children and adolescents with insulin-dependent diabetes mellitus over a four-year longitudinal follow-up: II. Immediate and long-term linkages with the family milieu. *J Pediatr Psychol*, 15(4): 527-42, 1990, [C] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Hauser_1990.pdf.
48. **Hauser, S. T.; Jacobson, A. M.; Wertlieb, D.; Weiss-Perry, B.; Follansbee, D.; Wolfsdorf, J. I.; Herskowitz, R. D.; Houlihan, J.; and Rajapark, D. C.:** Children with recently diagnosed diabetes: interactions within their families. *Health Psychol*, 5(3): 273-96, 1986, [C] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Hauser_1986.pdf.
49. **Haynes, R. B.; Yao, X.; Degani, A.; Kripalani, S.; Garg, A.; and McDonald, H. P.:** Interventions to enhance medication adherence. *Cochrane Database Syst Rev*, (4): CD000011, 2005, [M] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Haynes_2005.pdf.
50. **Hederos, C. A.; Janson, S.; and Hedlin, G.:** Group discussions with parents have long-term positive effects on the management of asthma with good cost-benefit. *Acta Paediatrica*, 94(5): 602-8, 2005, [B] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Hederos_2005.pdf.
51. **Hesse, M.:** The Readiness Ruler as a measure of readiness to change poly-drug use in drug abusers. *Harm Reduct J*, 3: 3, 2006, [O] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Hesse_2006_Readiness_Ruler.pdf.
52. **Hettema, J.; Steele, J.; and Miller, W. R.:** Motivational Interviewing. *Annual Review of Clinical Psychology*, 2005, [M] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Hettema_2005.pdf.
53. **Hibbard, J. H.; Mahoney, E. R.; Stockard, J.; and Tusler, M.:** Development and testing of a short form of the patient activation measure. *Health Serv Res*, 40(6 Pt 1): 1918-30, 2005, [O] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Hibbard_2005.pdf.
54. **Hibbard, J. H.; Stockard, J.; Mahoney, E. R.; and Tusler, M.:** Development of the Patient Activation Measure (PAM): conceptualizing and measuring activation in patients and consumers. *Health Serv Res*, 39(4 Pt 1): 1005-26, 2004, [O] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Hibbard_2004.pdf.
55. **Holden, G.:** The relationship of self-efficacy appraisals to subsequent health related outcomes: a meta-analysis. *Soc Work Health Care*, 16(1): 53-93, 1991, [M] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Holden_1991.pdf.
56. **Horan, P. P.; Yarborough, M. C.; Besigel, G.; and Carlson, D. R.:** Computer-assisted self-control of diabetes by adolescents. *Diabetes Educ*, 16(3): 205-11, 1990, [B] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Horan_1990.pdf.
57. **Institute of Medicine:** *Crossing the quality chasm : a new health system for the 21st century*. Washington, D.C., 2001, [E].
58. **Ireys, H. T.; Chernoff, R.; Stein, R. E. K.; DeVet, K. A.; and Silver, E. J.:** Outcomes of community-based family-to-family support: lessons learned from a decade of randomized trials. *Children's Services: Social Policy, Research, and Practice*, 4(4): 203-16. (40 ref), 2001, [S] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Ireys_2001.pdf.
59. **Jack, L., Jr.; Liburd, L.; Spencer, T.; and Airhihenbuwa, C. O.:** Understanding the environmental issues in diabetes self-management education research: a reexamination of 8 studies in community-based settings. *Ann Intern Med*, 140(11): 964-71, 2004, [M] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Jack_2004_SR_DiabetesEnvironmentfromAnita.pdf.
60. **Jacobson, A. M. et al.:** Adherence among children and adolescents with insulin-dependent diabetes mellitus over a four-year longitudinal follow-up: I. The influence of patient coping and adjustment. *J Pediatr Psychol*, 15(4): 511-26, 1990, [C] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Jacobson_1990.pdf.
61. **Jacobson, A. M.; Hauser, S. T.; Wolfsdorf, J. I.; Houlihan, J.; Milley, J. E.; Herskowitz, R. D.; Wertlieb, D.; and Watt, E.:** Psychologic predictors of compliance in children with recent onset of diabetes mellitus. *J Pediatr*, 110(5): 805-11, 1987, [O] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Jacobson_1987.pdf.
62. **Juniper, E. F.; Guyatt, G. H.; Feeny, D. H.; Ferrie, P. J.; Griffith, L. E.; and Townsend, M.:** Measuring quality of life in children with asthma. *Qual Life Res*, 5(1): 35-46, 1996a, [O] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Juniper_1996_Children.pdf.
63. **Juniper, E. F.; Guyatt, G. H.; Feeny, D. H.; Ferrie, P. J.; Griffith, L. E.; and Townsend, M.:** Measuring quality of life in the parents of children with asthma. *Qual Life Res*, 5(1): 27-34, 1996b, [O] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Juniper_1996_Parents.pdf.
64. **Kashikar-Zuck, S.; Swain, N. F.; Jones, B. A.; and Graham, T. B.:** Efficacy of cognitive-behavioral intervention for juvenile primary fibromyalgia syndrome. *J Rheumatol*, 32(8): 1594-602, 2005, [B] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_KashikarZuck_2005.pdf.
65. **Kazak, A. E.; Kazak, A. E.; Prusak, A.; McSherry, M.; Simms, S.; Beele, D.; Rourke, M.; Alderfer, M.; and Lange, B.:** The Psychosocial Assessment Tool (PAT) (c): Pilot data on a brief screening instrument for identifying high risk families in pediatric oncology. *Families, Systems & Health*, 2001, [O] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Kazak_2001.pdf.
66. **Kroeze, W.; Werkman, A.; and Brug, J.:** A systematic review of randomized trials on the effectiveness of computer-tailored education on physical activity and dietary behaviors. *Ann Behav Med*, 31(3): 205-23, 2006, [M] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Kroeze_2006.pdf.
67. **Lancaster, T., and Stead, L. F.:** Self-help interventions for smoking cessation. *Cochrane Database Syst Rev*, (3): CD001118, 2005, [M] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Lancaster_2005.pdf.
68. **Lemanek, K. L.; Kamps, J.; and Chung, N. B.:** Empirically supported treatments in pediatric psychology: regimen adherence. *J Pediatr Psychol*, 26(5): 253-75, 2001, [M] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Lemanek_2001.pdf.
69. **Lewin, S. A.; Skea, Z. C.; Entwistle, V.; Zwarenstein, M.; and Dick, J.:** Interventions for providers to promote a patient-centred approach in clinical consultations. *Cochrane Database Syst Rev*, (4): CD003267, 2001, [M] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Lewin_2004.doc.

70. Littlefield, C. H.; Craven, J. L.; Rodin, G. M.; Daneman, D.; Murray, M. A.; and Rydall, A. C.: Relationship of self-efficacy and binging to adherence to diabetes regimen among adolescents. *Diabetes Care*, 15(1): 90-4, 1992, [C] http://groups/p2/EBC/Files/Articles_Cited_in_CC_Guideline/Chronic_Littlefield_1992.pdf
71. **Local Consensus:** During guideline development timeframe. [E].
72. Lorig, K.; Chastain, R. L.; Ung, E.; Shoor, S.; and Holman, H. R.: Development and evaluation of a scale to measure perceived self-efficacy in people with arthritis. *Arthritis Rheum*, 32(1): 37-44, 1989, [O] http://groups/p2/EBC/Files/Articles_Cited_in_CC_Guideline/Chronic_Lorig_1989.pdf
73. Lorig, K.; Feigenbaum, P.; Regan, C.; Ung, E.; Chastain, R. L.; and Holman, H. R.: A comparison of lay-taught and professional-taught arthritis self-management courses. *J Rheumatol*, 13(4): 763-7, 1986, [B] http://groups/p2/EBC/Files/Articles_Cited_in_CC_Guideline/Chronic_Lorig_1986.pdf
74. Lorig, K. R., and Holman, H.: Self-management education: history, definition, outcomes, and mechanisms. *Ann Behav Med*, 26(1): 1-7, 2003, [S] http://groups/p2/EBC/Files/Articles_Cited_in_CC_Guideline/Chronic_Lorig_KR_2003.pdf
75. Lorig, K. R.; Laurent, D. D.; Deyo, R. A.; Marnell, M. E.; Minor, M. A.; and Ritter, P. L.: Can a Back Pain E-mail Discussion Group improve health status and lower health care costs?: A randomized study. *Arch Intern Med*, 162(7): 792-6, 2002, [A] http://groups/p2/EBC/Files/Articles_Cited_in_CC_Guideline/Chronic_Lorig_2002.pdf
76. Lorig, K. R.; Ritter, P.; Stewart, A. L.; Sobel, D. S.; Brown, B. W., Jr.; Bandura, A.; Gonzalez, V. M.; Laurent, D. D.; and Holman, H. R.: Chronic disease self-management program: 2-year health status and health care utilization outcomes. *Med Care*, 39(11): 1217-23, 2001, [C] http://groups/p2/EBC/Files/Articles_Cited_in_CC_Guideline/Chronic_Lorig_KR_2001a.pdf
77. Lorig, K. R.; Ritter, P. L.; Laurent, D. D.; and Fries, J. F.: Long-term randomized controlled trials of tailored-print and small-group arthritis self-management interventions. *Med Care*, 42(4): 346-54, 2004, [A] http://groups/p2/EBC/Files/Articles_Cited_in_CC_Guideline/Chronic_Lorig_KR_2004.pdf
78. Lorig, K. R.; Sobel, D. S.; Stewart, A. L.; Brown, B. W., Jr.; Bandura, A.; Ritter, P.; Gonzalez, V. M.; Laurent, D. D.; and Holman, H. R.: Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: a randomized trial. *Med Care*, 37(1): 5-14, 1999, [A] http://groups/p2/EBC/Files/Articles_Cited_in_CC_Guideline/Chronic_Lorig_KR_1999.pdf
79. Lozano, P. et al.: A multisite randomized trial of the effects of physician education and organizational change in chronic-asthma care: health outcomes of the Pediatric Asthma Care Patient Outcomes Research Team II Study. *Arch Pediatr Adolesc Med*, 158(9): 875-83, 2004, [A] http://groups/p2/EBC/Files/Articles_Cited_in_CC_Guideline/Chronic_Lozano_2004.pdf
80. Manley, M.; Epps, R. P.; Husten, C.; Glynn, T.; and Shopland, D.: Clinical interventions in tobacco control. A National Cancer Institute training program for physicians. *JAMA*, 266(22): 3172-3, 1991, [E] http://groups/p2/EBC/Files/Articles_Cited_in_CC_Guideline/Chronic_Manley_1991.pdf
81. Mash, R., and Allen, S.: Managing chronic conditions in a South African primary care context: exploring the applicability of Brief Motivational Interviewing. *SA Fam Pract*, 46(9): 21-26, 2004, [O] http://groups/p2/EBC/Files/Articles_Cited_in_CC_Guideline/Chronic_Mash_2004_Brief_MI.pdf
82. Michie, S.; Miles, J.; and Weinman, J.: Patient-centeredness in chronic illness: what is it and does it matter? *Patient Educ Couns*, 51(3): 197-206, 2003, [M] http://groups/p2/EBC/Files/Articles_Cited_in_CC_Guideline/Chronic_Michie_2003.pdf
83. Miller, W. R.: *Motivational Interviewing Training Workshop for Clinicians*. 2006, [E].
84. Miller, W. R., and Rollnick, S.: *Motivational interviewing: preparing people to change*. New York, 2002, [E].
85. Mishoe, S. C.; Baker, R. R.; Poole, S.; Harrell, L. M.; Arant, C. B.; and Rupp, N. T.: Development of an instrument to assess stress levels and quality of life in children with asthma. *J Asthma*, 35(7): 553-63, 1998, [O] http://groups/p2/EBC/Files/Articles_Cited_in_CC_Guideline/Chronic_Mishoe_1998.pdf
86. Modi, A. C.; Lim, C. S.; Yu, N.; Geller, D.; Wagner, M. H.; and Quittner, A. L.: A multi-method assessment of treatment adherence for children with cystic fibrosis. *J Cyst Fibros*, 5(3): 177-85, 2006, [O] http://groups/p2/EBC/Files/Articles_Cited_in_CC_Guideline/Chronic_Modi_2006.pdf
87. Monti, P. M.; Colby, S. M.; Barnett, N. P.; Spirito, A.; Rohsenow, D. J.; Myers, M.; Woolard, R.; and Lewander, W.: Brief intervention for harm reduction with alcohol-positive older adolescents in a hospital emergency department. *Journal of Consulting & Clinical Psychology*, 67(6): 989-94, 1999, [B] http://groups/p2/EBC/Files/Articles_Cited_in_CC_Guideline/Chronic_Monti_1999.pdf
88. Murray, E.; Burns, J.; See, T. S.; Lai, R.; and Nazareth, I.: Interactive Health Communication Applications for people with chronic disease. *Cochrane Database Syst Rev*, (4): CD004274, 2005, [M] http://groups/p2/EBC/Files/Articles_Cited_in_CC_Guideline/Chronic_Murray_2005.pdf
89. Newacheck, P. W.; Strickland, B.; Shonkoff, J. P.; Perrin, J. M.; McPherson, M.; McManus, M.; Lauver, C.; Fox, H.; and Arango, P.: An epidemiologic profile of children with special health care needs. *Pediatrics*, 102(1 Pt 1): 117-23, 1998, [O] http://groups/p2/EBC/Files/Articles_Cited_in_CC_Guideline/Chronic_Newacheck_1998.pdf
90. Nilsen, E. S.; Myrhaug, H. T.; Johansen, M.; Oliver, S.; and Oxman, A. D.: Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material. *Cochrane Database Syst Rev*, 3: CD004563, 2006, [M] http://groups/p2/EBC/Files/Articles_Cited_in_CC_Guideline/Chronic_Nilsen_2006.pdf
91. Norris, S. L.; Chowdhury, F. M.; Van Le, K.; Horsley, T.; Brownstein, J. N.; Zhang, X.; Jack, L., Jr.; and Satterfield, D. W.: Effectiveness of community health workers in the care of persons with diabetes. *Diabet Med*, 23(5): 544-56, 2006, [M] http://groups/p2/EBC/Files/Articles_Cited_in_CC_Guideline/Chronic_Norris_2006_SR_DiabetesLayWorkersSR_fromAnita.pdf
92. Norris, S. L.; Lau, J.; Smith, S. J.; Schmid, C. H.; and Engelgau, M. M.: Self-management education for adults with type 2 diabetes: a meta-analysis of the effect on glycemic control. *Diabetes Care*, 25(7): 1159-71, 2002a, [M] http://groups/p2/EBC/Files/Articles_Cited_in_CC_Guideline/Chronic_Norris_2002b.pdf
93. Norris, S. L. et al.: The effectiveness of disease and case management for people with diabetes. A systematic review. *Am J Prev Med*, 22(4 Suppl): 15-38, 2002b, [M] http://groups/p2/EBC/Files/Articles_Cited_in_CC_Guideline/Chronic_Norris_2002a.pdf
94. Norris, S. L. et al.: Increasing diabetes self-management education in community settings. A systematic review. *Am J Prev Med*, 22(4 Suppl): 39-66, 2002c, [M] http://groups/p2/EBC/Files/Articles_Cited_in_CC_Guideline/Chronic_Norris_2002c.pdf

95. **O'Connor, A. M.; Llewellyn-Thomas, H. A.; and Flood, A. B.:** Modifying unwarranted variations in health care: shared decision making using patient decision aids. *Health Aff (Millwood)*, Suppl Web Exclusive: VAR63-72, 2004, [S] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_OConner_2004.pdf.
96. **O'Connor, A. M. et al.:** Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev*, (2): CD001431, 2003, [M] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_OConner_2003.pdf.
97. **Parkin, P. C.; Kirpalani, H. M.; Rosenbaum, P. L.; Fehlings, D. L.; Van Nie, A.; Willan, A. R.; and King, D.:** Development of a health-related quality of life instrument for use in children with spina bifida. *Qual Life Res*, 6(2): 123-32, 1997, [O] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Parkin_1997.pdf.
98. **Patton, S. R.; Graham, J. L.; Varlotta, L.; and Holsclaw, D., Jr.:** Measuring self-care independence in children with cystic fibrosis: the Self-Care Independence Scale (SCIS). *Pediatr Pulmonol*, 36(2): 123-30, 2003, [O] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Patton_2003.pdf.
99. **Perrin, E. C. et al.:** Issues involved in the definition and classification of chronic health conditions. *Pediatrics*, 91(4): 787-93, 1993, [S] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Perrin_1993.pdf.
100. **Powell, H., and Gibson, P. G.:** Options for self-management education for adults with asthma. *Cochrane Database Syst Rev*, (1): CD004107, 2003, [M] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Powell_Options_for_selfmanagement_education_Cochrane_Jr_n2003.pdf.
101. **Quittner, A. L.; Buu, A.; Messer, M. A.; Modi, A. C.; and Watrous, M.:** Development and validation of The Cystic Fibrosis Questionnaire in the United States: a health-related quality-of-life measure for cystic fibrosis. *Chest*, 128(4): 2347-54, 2005, [O] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Quittner_2005.pdf.
102. **Raphael, D.; Rukholm, E.; Brown, I.; Hill-Bailey, P.; and Donato, E.:** The Quality of Life Profile--Adolescent Version: background, description, and initial validation. *J Adolesc Health*, 19(5): 366-75, 1996, [O] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Raphael_1996.pdf.
103. **Reimanis, C. L.; Cohen, E. L.; and Redman, R.:** Nurse case manager role attributes: fifteen years of evidence-based literature. *Lippincotts Case Manag*, 6(6): 230-9; quiz 240-2, 2001, [S] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Reimanis_2001.pdf.
104. **Renders, C. M.; Valk, G. D.; Griffin, S. J.; Wagner, E. H.; Eijk Van, J. T.; and Assendelft, W. J.:** Interventions to improve the management of diabetes in primary care, outpatient, and community settings: a systematic review. *Diabetes Care*, 24(10): 1821-33, 2001, [M] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Renders_2001.pdf.
105. **Resnicow, K.; Jackson, A.; Wang, T.; De, A. K.; McCarty, F.; Dudley, W. N.; and Baranowski, T.:** A motivational interviewing intervention to increase fruit and vegetable intake through Black churches: results of the Eat for Life trial. *Am J Public Health*, 91(10): 1686-93, 2001, [A] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Resnicow_2001.pdf.
106. **Riemsma:** A systematic review of the effectiveness of interventions based on a stages-of-change approach to promote individual behaviour change. *Health Technology Assessment (Winchester, England)*, 6(24):1-231, 2002., 6(24): 1-231, 2002, [M] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Riemsma_2002.pdf.
107. **Ritchie, J.; Stewart, M.; Ellerton, M.; Thompson, D.; Meade, D.; and Viscount, P. W.:** Parents' perceptions of the impact of a telephone support group intervention. *Journal of Family Nursing*, 6(1): 25-45, 2000, [A] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Ritchie_2000.pdf.
108. **Rollnick, S.; Mason, P.; and Butler, C.:** *Health behavior change : a guide for practitioners*. Edinburgh ; New York, 1999, [E].
109. **Rubak, S.; Sandbaek, A.; Lauritzen, T.; and Christensen, B.:** Motivational interviewing: a systematic review and meta-analysis. *Br J Gen Pract*, 55(513): 305-12, 2005, [M] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Rubak_2005.pdf.
110. **Rutishauser, C.; Sawyer, S. M.; Bond, L.; Coffey, C.; and Bowes, G.:** Development and validation of the Adolescent Asthma Quality of Life Questionnaire (AAQOL). *Eur Respir J*, 17(1): 52-8, 2001, [O] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Rutishauser_2001.pdf.
111. **Sabaz, M.; Cairns, D. R.; Lawson, J. A.; Nheu, N.; Bleasel, A. F.; and Bye, A. M.:** Validation of a new quality of life measure for children with epilepsy. *Epilepsia*, 41(6): 765-74, 2000, [O] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Sabaz_2000.pdf.
112. **Schneiderman, N.; Antoni, M. H.; Saab, P. G.; and Ironson, G.:** Health psychology: psychosocial and biobehavioral aspects of chronic disease management. *Annu Rev Psychol*, 52: 555-80, 2001, [S] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Schneiderman_2001.pdf.
113. **Smith, J. R.; Mugford, M.; Holland, R.; Candy, B.; Noble, M. J.; Harrison, B. D.; Koutantji, M.; Upton, C.; and Harvey, I.:** A systematic review to examine the impact of psycho-educational interventions on health outcomes and costs in adults and children with difficult asthma. *Health Technol Assess*, 9(23): 1-182, 2005, [M] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Smith_2005_SysRev.pdf.
114. **Spilker, B.:** Quality of life studies: Definitions and conceptual issues. In *Quality of life and pharmacoeconomics in clinical trials*, pp. xlv, 1259. Edited by Schipper, H., Clinch, J. J., Olweny, C. L., Philadelphia, Lippincott-Raven, 1996, [E].
115. **Staab, D. et al.:** Age related, structured educational programmes for the management of atopic dermatitis in children and adolescents: multicentre, randomised controlled trial. *BMJ*, 332(7547): 933-8, 2006, [A] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Staab_2006.pdf.
116. **Stein, R. E., and Silver, E. J.:** Comparing different definitions of chronic conditions in a national data set. *Ambul Pediatr*, 2(1): 63-70, 2002, [O] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Stein_2002_ChronicPopDefinitions.pdf.
117. **Stein, R. E., and Silver, E. J.:** Operationalizing a conceptually based noncategorical definition: a first look at US children with chronic conditions. *Arch Pediatr Adolesc Med*, 153(1): 68-74, 1999, [C] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Stein_1999.pdf.
118. **Stewart, M. A.:** Effective physician-patient communication and health outcomes: a review. *Cmaj*, 152(9): 1423-33, 1995, [M] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Stewart_1995_CollaborativeCommunication.pdf.
119. **Stille, C. J.; Jerant, A.; Bell, D.; Meltzer, D.; and Elmore, J. G.:** Coordinating care across diseases, settings, and clinicians: a key role for the generalist in practice. *Ann Intern Med*, 142(8): 700-8, 2005, [S] http://groups/p2/EBC/Files/Articles/Cited_in_CC_Guideline/Chronic_Stille_2005.pdf.

120. **Story, M.; Lytle, L. A.; Birnbaum, A. S.; and Perry, C. L.:** Peer-led, school-based nutrition education for young adolescents: feasibility and process evaluation of the TEENS study. *J Sch Health*, 72(3): 121-7, 2002, [O] http://groups/p2/EBC/Files/Articles_Cited_in_CC_Guideline/Chronic_Stille_2005.pdf.
121. **Task Force on Community Preventive Services:** Recommendations for healthcare system and self-management education interventions to reduce morbidity and mortality from diabetes. *Am J Prev Med*, 22(4 Suppl): 10-4, 2002, [S, E] http://groups/p2/EBC/Files/Articles_Cited_in_CC_Guideline/Chronic_TaskForce_2002.pdf.
122. **Thorne, S.:** Patient-provider communication in chronic illness: a health promotion window of opportunity. *Fam Community Health*, 29(1 Suppl): 4S-11S, 2006, [S] http://groups/p2/EBC/Files/Articles_Cited_in_CC_Guideline/Chronic_Thorne_2006.pdf.
123. **Toelle, B. G., and Ram, F. S.:** Written individualised management plans for asthma in children and adults. *Cochrane Database Syst Rev*, (2): CD002171, 2004, [M] http://groups/p2/EBC/Files/Articles_Cited_in_CC_Guideline/Chronic_Toelle_2004.pdf.
124. **Tsai, A. C.; Morton, S. C.; Mangione, C. M.; and Keeler, E. B.:** A meta-analysis of interventions to improve care for chronic illnesses. *Am J Manag Care*, 11(8): 478-88, 2005, [M] http://groups/p2/EBC/Files/Articles_Cited_in_CC_Guideline/Chronic_Tsai_AJMC_2005.pdf.
125. **Varni, J. W.; Katz, E. R.; Seid, M.; Quiggins, D. J.; and Friedman-Bender, A.:** The pediatric cancer quality of life inventory-32 (PCQL-32): I. Reliability and validity. *Cancer*, 82(6): 1184-96, 1998, [O] http://groups/p2/EBC/Files/Articles_Cited_in_CC_Guideline/Chronic_Varni_1998.pdf.
126. **Von Korff, M.; Gruman, J.; Schaefer, J.; Curry, S. J.; and Wagner, E. H.:** Collaborative management of chronic illness. *Ann Intern Med*, 127(12): 1097-102, 1997, [S] http://groups/p2/EBC/Files/Articles_Cited_in_CC_Guideline/Chronic_VonKorff_1997.pdf.
127. **Von Korff, M.; Moore, J. E.; Lorig, K.; Cherkin, D. C.; Saunders, K.; Gonzalez, V. M.; Laurent, D.; Rutter, C.; and Comite, F.:** A randomized trial of a lay person-led self-management group intervention for back pain patients in primary care. *Spine*, 23(23): 2608-15, 1998, [A] http://groups/p2/EBC/Files/Articles_Cited_in_CC_Guideline/Chronic_VonKorff_1998.doc.
128. **Wagner, E. H.:** Chronic disease management: what will it take to improve care for chronic illness? *Eff Clin Pract*, 1(1): 2-4, 1998, [E] http://groups/p2/EBC/Files/Articles_Cited_in_CC_Guideline/Chronic_Wagner_1998.pdf.
129. **Wagner, E. H.; Austin, B. T.; and Von Korff, M.:** Organizing care for patients with chronic illness. *Milbank Q*, 74(4): 511-44, 1996, [S] http://groups/p2/EBC/Files/Articles_Cited_in_CC_Guideline/Chronic_Wagner_1996.pdf.
130. **Wagner, E. H.; Bennett, S. M.; Austin, B. T.; Greene, S. M.; Schaefer, J. K.; and Vonkorff, M.:** Finding common ground: patient-centeredness and evidence-based chronic illness care. *J Altern Complement Med*, 11 Suppl 1: S7-15, 2005, [S] http://groups/p2/EBC/Files/Articles_Cited_in_CC_Guideline/Chronic_Wagner_2005.pdf.
131. **Wagner, E. H.; Davis, C.; Schaefer, J.; Von Korff, M.; and Austin, B.:** A survey of leading chronic disease management programs: are they consistent with the literature? *Managed Care Quarterly*, 7(3): 56-66, 1999, [O] http://groups/p2/EBC/Files/Articles_Cited_in_CC_Guideline/Chronic_Wagner_1999.pdf.
132. **Ware, J. E., Jr., and Sherbourne, C. D.:** The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. *Med Care*, 30(6): 473-83, 1992, [O] http://groups/p2/EBC/Files/Articles_Cited_in_CC_Guideline/Chronic_Ware_1992.pdf.
133. **Wasson, J. H.; Ahles, T.; Johnson, D.; Kabcenell, A.; Lewis, A.; and Godfrey, M. M.:** Resource planning for patient-centered, collaborative care. *J Ambul Care Manage*, 29(3): 207-14, 2006, [O] http://groups/p2/EBC/Files/Articles_Cited_in_CC_Guideline/Chronic_Wasson_2006b.pdf.
134. **Wasson, J. H.; Johnson, D. J.; Benjamin, R.; Phillips, J.; and MacKenzie, T. A.:** Patients report positive impacts of collaborative care. *J Ambul Care Manage*, 29(3): 199-206, 2006, [C] http://groups/p2/EBC/Files/Articles_Cited_in_CC_Guideline/Chronic_Wasson_2006a.pdf.
135. **Weingarten, S. R.; Henning, J. M.; Badamgarav, E.; Knight, K.; Hasselblad, V.; Gano, A., Jr.; and Ofman, J. J.:** Interventions used in disease management programmes for patients with chronic illness-which ones work? Meta-analysis of published reports.[see comment]. *BMJ*, 325(7370): 925, 2002, [M] http://groups/p2/EBC/Files/Articles_Cited_in_CC_Guideline/Chronic>Weingarten_2002.pdf.
136. **Whitlock, E. P.; Orleans, C. T.; Pender, N.; and Allan, J.:** Evaluating primary care behavioral counseling interventions: an evidence-based approach. *Am J Prev Med*, 22(4): 267-84, 2002, [S] http://groups/p2/EBC/Files/Articles_Cited_in_CC_Guideline/Chronic_Whitlock_2002.pdf.
137. **Wolf, F. M.; Guevara, J. P.; Grum, C. M.; Clark, N. M.; and Cates, C. J.:** Educational interventions for asthma in children. *Cochrane Database Syst Rev*, (1): CD000326, 2003, [M] http://groups/p2/EBC/Files/Articles_Cited_in_CC_Guideline/Chronic_Wolf_2003.doc.
138. **Wysocki, T.:** Behavioral assessment and intervention in pediatric diabetes. *Behav Modif*, 30(1): 72-92, 2006, [S] http://groups/p2/EBC/Files/Articles_Cited_in_CC_Guideline/Chronic_Wysocki_2006b_Behav_Modif.pdf.
139. **Wysocki, T.; Harris, M. A.; Buckloh, L. M.; Mertlich, D.; Lochrie, A. S.; Taylor, A.; Sadler, M.; Mauras, N.; and White, N. H.:** Effects of Behavioral Family Systems Therapy for Diabetes on Adolescents' Family Relationships, Treatment Adherence, and Metabolic Control. *J Pediatr Psychol*, 2006, [A] http://groups/p2/EBC/Files/Articles_Cited_in_CC_Guideline/Chronic_Wysocki_2006a_Behav_Fam_Sys.pdf.
140. **Wysocki, T.; Harris, M. A.; Greco, P.; Bubb, J.; Danda, C. E.; Harvey, L. M.; McDonell, K.; Taylor, A.; and White, N. H.:** Randomized, controlled trial of behavior therapy for families of adolescents with insulin-dependent diabetes mellitus. *J Pediatr Psychol*, 25(1): 23-33, 2000, [A] http://groups/p2/EBC/Files/Articles_Cited_in_CC_Guideline/Chronic_Wysocki_2000_Rand_Control.pdf.
141. **Yorke, J.; Fleming, S.; and Shuldham, C.:** Psychological interventions for children with asthma. *Cochrane Database Syst Rev*, (4): CD003272, 2005, [M] http://groups/p2/EBC/Files/Articles_Cited_in_CC_Guideline/Chronic_Yorke_2005.pdf.