Supplementary Online Content

Cohen E, Jovcevska V, Kuo DZ, Mahant S. Hospital-based comprehensive care programs for children with special health care needs: a systematic review. *Arch Pediatr Adolesc Med*. 2011;165(6):554-561.

eTable 1. Example of Search Strategy (Ovid MEDLINE)
eTable 2. Characteristics and Evaluation of Programs Meeting Inclusion Criteria (Expansion of Table 1 and Table 2)

This supplementary material has been provided by the authors to give readers additional information about their work.

eTable 1. Example of Search Strategy (Ovid MEDLINE)

Arthritis/ or exp arthritis, rheumatoid/ or Cerebral Palsy/ or exp Anemia, Sickle Cell/ or exp Diabetes Mellitus/ or exp Asthma/ or Cystic Fibrosis/ or exp Spinal Dysraphism/ or exp HIV/ or exp hiv infections/ or kidney failure, chronic/ or exp renal insufficiency, chronic/ or exp Mental Retardation/ or Short Bowel Syndrome/ or chronic disease/ or disabled child/ or (special adj2 need:).ti,ab. or (medical: adj2 complex:).ti,ab. or (technolog: adj2 dependen:).ti,ab. or (medical: adj2 fragil:).ti,ab. or (complex adj2 need:).ti,ab. (1048522)

Patient Transfer/ or exp Patient Care Management/ or health services accessibility/ or (medical adj2 home:).ti,ab. or ((care adj2 coordinat:) or (care adj2 co-ordinat:)).ti,ab. or (case adj2 manage:).ti,ab. (425432)

1 and 2 (36377)

Limit 3 to "all child (0 to 18 years)" (8599)

Pediatrics/ or (pediatric: or paediatric: or child: or infan: or teen: or adolescen: or (young adj2 adult:)).mp. (2742567)

3 and 5 (9602)

4 or 6 (9602)

Limit 7 to (evaluation studies or validation studies) (298)

Evaluation studies as topic/ or clinical trials as topic/ or program evaluation/ or validation studies as topic/ or clinical trial.pt. or clinical trial, phase i.pt. or clinical trial, phase ii.pt. or clinical trial, phase iii.pt. or clinical trial, phase iv.pt. or controlled clinical trial.pt. or meta-analysis.pt. or multicenter study.pt. or randomized controlled trial.pt. or exp clinical trials as topic/ (934057)

7 and 9 (1333)

8 or 10 (1501)

Limit 11 to yr="2008 -Current" (398)

eTable 2. Characteristics and Evaluation of Programs Meeting Inclusion Criteria (Expansion of Table 1 and Table 2)

Program	Patient Population	Intervention/Control*	Study Design	Quality Rating (out of 36)	Outcomes (quality ain; results)
(A) Categorical Patient Populations					
Early Hospital Discharge & Home Follow-Up, Philadelphia, PA[25]	Low birth weight infants	o Home follow-up care from RN after early discharge o Promoting interaction between parent/infant & education o Control group: standard discharge	RCT	27	• Length of Hospital Stay (e1/e2; ↓) • Physical Development (e1; ∅) • Re-hospitalization (e1/e2; ∅) • Acute care visits (e1/e2; ∅) • Program Cost (e2; ↓) • Physicians' Charge (e2; ↓)
Comprehensive Follow-Up Care, Dallas, TX, USA[26]	Low birth weight infants	o Comprehensive care ▪ Well-baby & chronic illness care ▪ RN or MD available 24 hours for acute problems ▪ Home visits o Control group: routine follow-up care (well-baby & chronic illness care)	RCT	30	• Treatment Compliance (e1; ↑) • Emergency Department Visits (e1/e2 ↓) • Life Threatening Illness (e1/s; ↓) • Intensive Care Services (e1; ↓) • Intensive Care Admissions (e1/e2; ↓) • Days in Intensive Care Unit (e1/e2; ↓) • Program Cost (e2; ↓) • Deaths (e1/s; ∅) • Hospital Admissions (e1/e2; ∅) • Length of

					Hospital Stay (e1/e2; ∅)
The Pediatric Asthma Intervention, Chicago, IL, USA[27]	Asthma	o Reinforced Asthma Education ▪ Monthly contact by team & encouragement to call & ask questions o Reinforced Asthma Education & Case Management ▪ In addition, action plan provided ▪ Nurse practitioner available for other issues o Control group: 1 individualized education session	RCT	25	• Clinic Visits (e1/e2; ↓) • Hospital Admissions (e1/e2; ∅) • Length of Hospital Stay (e1/e2; ∅) • Emergency Department Visits (e1/e2; ∅) • Health Care Reimbursement (e2; ∅) • Program Cost Savings (e2; ∅)
Education & Telephone Case Management for Children with Type 1 Diabetes, Philadelphia, PA, USA[28]	Type 1 diabetes	o Education & Telephone Case Management intervention ▪ Review guidelines, health & safety ▪ Problem solve ▪ Meal planning ▪ Behaviour & parenting o Single education session & customized written guides intervention o Control group: standard care	RCT	31	• Adherence to Treatment (e1; ↑) • Parent/Child Teamwork for Disease Management (p; ↑) • Parents' Knowledge of Child's Condition (p; ∅) • Glycemic Control (e2; ∅)
Care Ambassador Program, Boston, MA, USA[29]	Type 1 diabetes	o Care Ambassador provided ▪ Care coordination (appointment scheduling,	RCT	28	• Severe Hypoglycemia (e1/s; ↓) • Hospital Admissions (e1/e2; ↓) • Emergency

		addressing questions, direct families to resources) ▪ Clinic attendance monitoring with outreach for missed appointments o Care Ambassador plus provided additional ▪ Psycho-education with written material ▪ Time per visit spent with patients o Control group: standard multidisciplinary care			Department Visits (e1/e2; ↓) • Glycemic Control (e2; ↑)
The Pediatric Asthma Center Comprehensive Inner-City Asthma Program, Bronx, NY, USA[30]	Asthma	o Multidisciplinary, hospital-based specialty clinic ▪ Provided intensive medical & environmental control, education & monitoring ▪ 24 hour availability o Control group: care continued by other health resources	RCT	32	• Emergency Department Visits (e1/2; ↓) • Hospital Admissions (e1/2; ↓)
Earlier Discharge with Community-Based Intervention, Winnipeg, MB, Canada[31]	Low birth weight infants	o Early discharge with follow-up in the community ▪ Public health nurse & homemaker services for 8 weeks post-discharge ▪ Assessment	RCT	29	• Length of Hospital Stay (e1/e2; ↓) • Rehospitalization Rate (e1/e2; ∅) • Illness Rate (e2; ∅) • Health Care Team Home Visits/Phone Contacts

		, education, support & referral/liaison to other services ▪ Home visit or telephone contact ▪ Nurse always available o Control group: standard discharge			(e1/e2/p; ↑) • Physical Development (e1; ∅) • Quality of the Home Environment (e1;p ↑) • Program Cost (e2; ↓)
Home and Ambulatory Program for Asthmatic Children, Halifax, Nova Scotia, Canada[32]	Asthma	o Comprehensive home & ambulatory program ▪ Education & home visits by specially trained nurse o Control group: continued to received standard care	RCT	29	• Illness Severity (e1;↓) • Illness Symptoms (e1; ∅) • Medication Requirements (e1; ∅) • Primary Care Physician Visits (e1/e2; ↓) • Hospital Admissions (e1/e2; ∅) • Multiple Hospital Admissions (e1/e2; ↓) • Length of Hospital Stay (e1/e2; ∅) • Pulmonary Function (e1; ↑) • School Absenteeism (e1;↓) • Metered Aerosol Technique (e1; ↑) • Reduction of Smokers Living at Home (e1; ∅) • Reduction in Number of Pets (e1; ∅) • Asthma

					Education Questionnaire (e1; ↑) • Family Satisfaction with Care (p; ∅) • Family Wanting More Information (p; ↓)
Home-Based Management, Montreal, QC, Canada[33]	Type 1 diabetes	o Hospital-based intervention ▪ Patients remained in hospital for metabolic stabilization & initial insulin therapy ▪ Education by nurse, dietician, & diabetologist with additional sessions as needed o Home-based intervention ▪ In addition, diabetes treatment nurse accompanied family home ▪ Offered flexible education sessions ▪ Implemented insulin treatment plan with diabetologist	RCT	28	• Metabolic Control (e1; ↑) • Illness Related Adverse Events (e1/s; ∅) • Parents' Knowledge of Child's Condition (p; ∅) • Parent/Child Adherence to Treatment (p; ∅) • Impact of Child's Illness on Family (p; ∅) • Parental Perceived Stress (p; ∅) • Family Satisfaction with Care (p; ∅) • Child Stress Scale (e1; ↑) • Parental Out-of-Pocket Expenses (e2; ↓) • Parental Time Spent with Hospitalized Child (p; ↓) • Parental Hours Missed from Work (p; ∅)
After Care	Low birth weight	o Home health	RCT	28	• Emergency

Services, Los Angeles, CA, USA[34]	infants	intervention ▪ Provided critical home care in first 1 to 4 weeks post-discharge ▪ Physician available for consult 24hours/day o Home visit intervention ▪ Provided prevention & intervention services ▪ Focus on development & health monitoring of infant, parental support & social service referrals ▪ First 2 years post-discharge o Home health & home visit combined intervention o Control group: received no in-home assistance			Department Visits (e1/e2; ∅) • Rehospitalization (e1/e2; ∅) • Immunization Status (e1; ↑)
Follow-up Care for Infants with Chronic Lung Disease, Winston-Salem, North Carolina, USA[35]	Chronic lung disease	o Community-based follow-up ▪ Nurse specialist monitored infants' & parents' health & resources use ▪ Made referrals o Center-based follow-up ▪ Visits to a medical multidisciplinary clinic ▪ Developed	RCT	34	• Physical and Mental Development (e1; ∅) • Rehospitalization (e1/e2; ∅) • Respiratory Illness (e1; ∅)

		plan of care ▪ Update letter to PCP following visits			
Military Community Asthma Program (MilCAP), Honolulu, HI, USA[36]	Asthma	o Run by team coordinator, parent educator & pulmonologist o Outpatient management plan o Education o Additional outpatient intervention for some families	Pre/Post	19	• Hospital Admissions (e1/e2; ↓)
CLT, London, UK[37]	Visual impairment/ophthalmic disorders	o Hospital-based community link team members o Accompanied families during assessments o Reinforced & clarified clinical information o Advised families about visual stimulation programs o Education & social services information o First contact point parents	Pre/Post	23	• Family-Centeredness of Care (p; ∅) • Family Satisfaction with Care (p; ↑)
Comprehensive Clinical Care Program, Cotonou, Republic of Benin[38]	Sickle Cell Disease	o Intensive parental education & information sessions o Education was repeated with encouragement for ▪ Vaccination ▪ Attending appointments ▪ Improving nutrition ▪ Malaria prophylaxis	Pre/Post	27	• Disease-Related Acute Events (e1; ↓) • General Status and Physical Growth (e1; ↑) • Hospitalization Frequency (e1/e2; ↓)
Multidisciplinary Clinic for	Epilepsy	o Medical management	Descriptive	26	• Family Satisfaction

Children with Epilepsy, Little Rock, AR, USA[39]		o Treatment plan involving optimal service control & multifaceted education o Direct intervention for psychosocial difficulties			with Care (p; ↑)
The Ocular Genetics Program, Toronto, ON, Canada[40]	Ocular genetics diseases	o Comprehensive & multidisciplinary hospital-based care o Centralized medical services, leading-edge molecular diagnosis o Goal to minimize visits o Optimized use of alternative care-givers & diverse resources	Descriptive	19	• Family Satisfaction with Care (p; ↑)
The Cystic Fibrosis Outreach Services (CFOS), Brisbane, AU[41]	Cystic Fibrosis	o Outreach in seven remote sites o Multidisciplinary team: ▪ Respiratory physician, physiotherapist, dietitian and nurse ▪ Local paediatricians, general practitioners and/or health workers o Clinics occur at least once per year o Control group: Tertiary CF centre	Retrospective Cohort	34	• Pulmonary Function (e1; ∅) • Sputum Bacteriology (e1; ∅) • Physical Development (e1; ∅) • Hospital Admissions (e1/e2; ↓)
(B) Non-Categorical Patient Populations					
Pediatric Home Care, Bronx, NY, USA[17,19,42]	Diverse chronic physical conditions including sick cell anemia, asthma,	o Community & hospital based intervention ▪ Multidisciplin	RCT	32	• Family Satisfaction with Care (p; ↑)

	diabetes, leukemia, juvenile rheumatoid arthritis and congenital conditions	ary team ▪ Comprehensive services, case management, coordination of services, monitoring, direct care, education & advocacy o Control group: standard care			• Child's Psychological Adjustment (e1/e2; ↑) • Parents' Well-Being (p; ↑) • Child's Function Status (e1; ∅) • Impact of Child's Illness on Family (p; ∅)
Project CATCH, Columbus, OH, USA[43]	Infants with moderate to severe bronchopulmonary dysplasia or neurologic dysfunction	o Hospital run community-based ▪ Multidisciplinary transition team o Control group: standard discharge & follow-up	RCT	26	• Services Accessed by Families (p; ↑) • Parental Social Support (p; ↑) • Physical and Mental Development (e1; ↑)
Integrated Health Care Program for Children with Special Needs, Michigan, USA[44]	Severe, chronic or handicapping conditions	o Hospital only integrated clinic ▪ Collaborative interdisciplinary model of care ▪ Visits in 1 place/ time ▪ Non-medical interventions ▪ Yearly comprehensive evaluation o Control group: traditional clinics	Prospective Cohort	30	• Child Behaviour (e1; ↑) • Parental Coping and Well-Being (p; ∅) • Child Coping and Well-Being (e1; ∅)
Project Continuity, Omaha, NE, USA[55]	Infants with developmental disabilities or chronic conditions	o Hospital-based comprehensive care coordination intervention o Individual & team care management o Assessment of family's needs & priorities o Intervention plan	Descriptive	22	• Timely access to Appropriate Services (t; ↑) • Parents' Knowledge of Child's Condition (p; ↑) • Parents' Participation

		developed o Referrals to other agencies o Follow-up care for care continuity & community transition			in Child's Care (p; ↑)
SABH Project, Stockholm, Sweden[56]	Infants with congenital malformations, premature infants in need of oxygen therapy and tube feeding, children with severe burn injuries, patients in advanced post-surgical care, multi-handicapped with acute complications, who were failing to thrive, oncological patients and those requiring terminal care.	o Hospital-managed advanced inpatient medical care at home o 24 hour support from paediatricians & specialized medical staff	Descriptive	16	• Hospital Admissions (e1/e2; ↓)
Comprehensive Ambulatory Services, Rochester, NY, USA[57]	Chronic conditions as defined by the International Classification of Diseases, Ninth Revision, Clinical Modification	o Multidisciplinary team to expand ambulatory care coordination & provide 'wraparound' services	Descriptive	27	• Length of Hospital Stay (e1/e2; ↓) • Hospital Admissions (e1/e2; ↓) • Hospital Charges (e2; ↓)
Special Primary Care Clinic, Denver, CO, USA[45]	Multisystem disorders behavioural/mental health, developmental delay and chromosomal/congenital diagnoses	o Hospital-based multidisciplinary team o Comprehensive primary care clinic o Care coordination & case management	Pre/Post	29	• Length of Hospital Stay (e1/e2; ↓) • Use of Needed Services (e1; ↑)
Pediatric Alliance for Coordinated Care, Boston, MA, USA[46]	Mental disorders, diseases of nervous system/sense organs, conditions originating in prenatal period, congenital abnormalities and symptoms, signs, ill-defined conditions and organ-specific conditions.	o Joint hospital & community intervention o Pediatric primary care providers & specialist providing integrated care o Managed by pediatric nurse practitioner	Pre/Post	33	• Ease of family care delivery (e1; ↑) • Access to Medical Team/Resources (e1; ↑) • Parents' Knowledge of Child's

		o Individualized health plan developed & shared with stakeholders			Condition (p; ↑) • Family Satisfaction with Care (p; ↑) • Relationship with Medical Team (p; ↑) • Parental Days Missed from Work (p; ↓) • Hospital Admissions (e1/e2; ↓)
Accelerated Care through Emergency Program, Melbourne, Australia[47]	Complex health care needs with underlying neurological problems, cared for by child development and rehabilitation service, multiple medical or ancillary services	o Hospital-based ED program o 24-hour care with nurses in conjunction with subspecialists o Clinical pathway with individual care plans developed	Pre/Post	29	• Family Satisfaction with Care (p; ↑) • Avoided Emergency Department Visits (e1/e2; ↑) • Program Cost Savings (e2; ↑) • Emergency Department Wait Times (t; ∅)
Access to Better Care Program, Columbus, OH, USA[48]	Special health care needs including sickle cell anemia and cerebral palsy	o Staffed by community- & hospital-based physicians & case managers (social workers/clinical nurse specialists) o 24 hour phone line	Pre/Post	26	• Parents' Knowledge of Child's Condition (p; ↑) • Family Satisfaction with Care (p; ↑) • Hospital Admissions (e1/e2; ↓) • Program Cost Savings (e2; ∅)
Children with Special Needs Disease Management Program,	Juvenile-onset diabetes; Sickle cell disease; Complex congenital heart disease; neurological devastation; Genetic	o Staffed by advanced practice nurse case managers o Assessments completed to	Pre/Post	21	• Family Satisfaction with Care (p; ↑) • Hospital Admissions

Baltimore, MD, USA[49]	syndromes; Multiple comorbidities	develop care plan to meet short- & long-term goals o Coordination, facilitation of communication & collaboration, advocating for patients/families			(e1/e2; ↓) • Length of Hospital Stay (e1/e2; ↓) • Program Cost (e2; ↓) • Program Cost Savings (e2; ↑) • Emergency Department Visits (e1/e2; ↑)
Tertiary Care-Primary Care Partnership Model, Milwaukee, WI, USA[50]	Wide ranging chronic disorders involving multiple specialists, organ systems, unknown or uncertain diagnoses, multiple hospital admissions and medical visits	o Care coordination provided by nurse case manager ▪ Children with more frequent/longer hospitalizations were also treated by MD o Single point of contact at hospital between patients/families, PCPs & community resources o Care plans developed o Psychosocial support	Pre/Post	31	• Hospital Admissions (e1/e2; ↓) • Number of Hospital Days (e1/e2; ↓) • Hospital Charges (e2; ↓) • Use of Outpatient Services (e1/e2; ↑)
Chronic Complex Center, Tampa, Florida, USA[51]	Diverse; most commonly asthma, convulsions, cerebral palsy, cystic fibrosis, and lack/delay of physiological development	o Hospital-based medical home	Pre/Post	17	• Emergency room visits (e1/2; ↓) • Hospital admissions (e1/2; ↓) • Hospital days (e1/2; ↓) • Costs (e2; ↓)
Complex Care Clinic, Toronto, ON, Canada[52]	≤ 18 yo with chronic health problems expected to continue for at least 12 months, that affected multiple organ systems, requiring treatment with	o Staffed by pediatrician and nurse practitioner focusing on management and co-ordination	Pre/Post	30	• Hospitalized days (e1/2; ↓) • Hospitalizations (e1/2; ∅) • Emergency department visits(e1/2; ∅) • Hospital

	multiple prescription medications and/or technological therapies, ongoing care by multiple medical sub-specialists and multiple allied health professionals in multiple health care settings. Excluded children enrolled in a comprehensive multi-disciplinary program for a single disease entity and children whose parents were unable to communicate in English.	o Comprehensive ambulatory follow-up in co-ordination with the child's primary care physician o Written care plans o Communication by e-mail or phone whenever possible			outpatient visits (e1/2; ↑) • Community outpatient visits (e1/2; ∅) • Parental QOL (p; ↑) • Family-centredness of care (p; ↑) • Parental satisfaction (p; ↑)
U Special Kids Program, Minneapolis, Minnesota, USA[53]	Four or more chronic medical problems, multiple medical specialists, numerous or rare medications, repeated hospitalizations and/or emergency room visits, technology dependence, needs not met by another service	o Coordinates communication between family, tertiary care services, social services, primary care provider, specialists, schools, insurers. o Documentation in electronic health record o Issues addressed by telephone when possible	Pre/Post	27	• Unplanned admissions/days (e1/2; ↓) • Planned admissions/day (e1/2; ∅)
Pediatric Medical Home Program at UCLA, Los Angeles, CA[54]	≥1 yo who see at least 2 different subspecialists on an ongoing basis; excludes solid organ transplant and patients seen in adolescent continuity settings.	o 60 minute initial visit for comprehensive evaluation o Follow-up appointments twice the length of standard visits o "Family Liaison" served as primary contact for families, attended appointment, provided translation services and coordinated follow-up	Pre/Post	28	• ED visits (e1/2; ↓) • Outpatient visits (e1/2; ∅) • Urgent care visits (e1/2; ∅) • Hospital admissions (e1/2; ∅) • Hospital days (e1/2; ∅) • LOS (e1/2; ∅)

		appointments and procedures o "All About Me" binder containing comprehensive health information			

Abbreviations: e1, effectiveness of care; e2, efficiency of care; e3, equity of care; p, patient/family centeredness; s, patient safety; t, timeliness; ↓, decrease in outcome measure; ↑, increase in outcome measure; ∅, no change in outcome measure.