Ana Johnson
and
Thérèse Stukel
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Medical Practice Variations in Pediatric Care

Patricia Tak Sam Li[1, 8], David C. Goodman[2, 3, 4, 5] and Astrid Guttmann[6, 7]
(1)Montreal Children's Hospital, McGill University Health Centre, 1001 Boulevard Décarie, H4A 3J1 Montreal, QC, Canada

(2)The Dartmouth Institute for Health Policy & Clinical Practice, Lebanon, NH, USA

(3)Department of Pediatrics, Dartmouth Hitchcock Medical Center, Lebanon, NH, USA

(4)Department of Community and Family Medicine, Dartmouth Hitchcock Medical Center, Lebanon, NH, USA

(5)Geisel School of Medicine at Dartmouth, Hanover, NH, USA

(6)Institute for Clinical Evaluative Sciences (ICES), 2075 Bayview Avenue, Suite G106, M4N 3M5 Toronto, ON, Canada

(7)Department of Paediatrics and Health Policy, Management and Evaluation, University of Toronto, Toronto, ON, Canada

(8)Department of Pediatrics, McGill University, Montreal, QC, Canada

Patricia Tak Sam Li (Corresponding author)
Email: patricia.li@mcgill.ca

David C. Goodman
Email: david.goodman@dartmouth.edu

Astrid Guttmann
Email: astrid.guttmann@ices.on.ca

Abstract

The study of pediatric medical practice variation began with reports on tonsillectomy rates in children almost a century ago. However, the majority of studies have only been conducted in the past two decades. The study of variations is important in revealing problems with healthcare systems and practice, and can be used to improve processes and outcomes in the care of children. However, there are some key issues that have hindered growth in pediatric variation studies, such as matters related to the ecology of disease and healthcare use unique to children, the paucity of evidence-based care, the relative lack of child health services capacity and population-based data, and other issues related to child health research in general (the four "D"s, which include Differential epidemiology, Developmental change, Dependency, and Demographics). This chapter examines methodological issues in child health and health services research that have challenged the study of pediatric practice variations, and examines variations in terms of effective care, preference-based care, and supply-sensitive care as it pertains to primary care and hospital care of children. Consideration of how

variations studies and pediatric care networks are using variations work and benchmarking to drive quality improvement efforts will be discussed. This chapter ends with an exploration of future directions in the pediatric field of medical practice variations.

Introduction

Historical Context: Variations in Pediatric Practice

Origins of the Study of Medical Variations: Tonsillectomies in Children, 1908–1938

The study of medical practice variations originated in the field of pediatrics almost a century ago, with the documentation of tonsillectomies (surgical removal of tonsils) in England and Wales (Goodman *2009*). As part of policy reforms to improve the health of children, the Parliament passed the Education (Administrative Provisions) Act of 1907, which required education authorities to provide medical inspection of children routinely at school. The School Medical Service became an important source of primary preventive care, where disease and poor health could be detected and treated in a more timely fashion (Harris *1995*). In his annual report, the Chief Medical Officer documented rates of common "defects," including the diagnosis of adenoids and enlarged tonsils, which rose from 4 % in 1920 to 6 % in 1931 (Board of Education *1920*, *1931*). Concurrently, the number of tonsillectomies increased (Table 1). By 1931, tonsillectomies represented 75 % of all procedure performed on English and Welsh school-aged children (Board of Education *1931*).**Table 1**
Number of tonsillectomies officially recorded annually in public elementary school children for London and England and Wales respectively (Reprinted from Glover (*1938*) with permission from SAGE Publications Ltd.))

Year	London	England and Wales
1919	11,817	42,004
1920	–	55,293
1923	7,656	47,685
1924	8,051	49,436
1925	12,179	60,871
1926	13,165	68,250

1927	14,843	80,548
1928	17,372	92,171
1929	17,186	97,518
1930	18,119	109,738
1931	18,178	110,239
1932	15,558	95,875
1933	11,436	77,564
1934	9,715	73,259
1935	9,959	73,763
1936	9,937	80,676
1937	10,198	84,414

Pioneers in Small Area Variation: J. A. Glover and J. Wennberg

In his seminal report entitled "The Incidence of Tonsillectomy in School Children" printed in 1938 in the *Proceedings of the Royal Society of Medicine*, Dr. J. Alison Glover was the first to publish research on tonsillectomies in epidemiological terms and conduct what became to be known as small area variation analysis (Glover *1938*). The latter novel approach, which would become an integral method used in health services research, examined healthcare resources and use across service areas. Specifically, he calculated incidence rates by place, using the local educational authorities as unit of analyses. Glover noted a tenfold variation in tonsillectomy rates across local educational authorities, as well as variations in rates by age, sex, and socioeconomic status (they were threefold greater in the "well-to-do"). He concluded that the observed variation was due to differing medical opinions on surgical indications for the enlarged tonsils. Glover's work was the first attempt to understand variations in practice and bring to light some of its implications.

The field of variations within pediatric medical practice remained relatively stagnant until 35 years later, when J. Wennberg and A. Gittelson published their work on small area variations in hospital services in Vermont (Wennberg and Gittelsohn *1973*). In this landmark study, they analyzed variations from the point of view of supply (in terms of number of hospital beds, personnel, physicians, and expenditures) and utilization (in terms of admission rates) across hospital service areas. They described a variation of greater than 50 % for supply across service areas per capita, and hospital admission rates that were 2–3 times different for most medical and surgical conditions examined. The rates of tonsillectomies also varied greater than tenfold. They made two important conclusions about the influence of physician supply on variations: that it impacted demand and

subsequent utilization, while having no relationship to needs of the population. Similar to their predecessor Glover, Wennberg and Gittelson also concluded that the variations observed were likely associated with the beliefs of the physicians rather than the incidence of disease. In their paper, they advocated for population-based health information systems, as a means to measure health system performance, which could lead to "rational public policy for health." For over 40 years, Wennberg and his colleagues at Dartmouth have strived to achieve the latter, with the creation of the *Dartmouth Atlas of Health Care* (*2015*) and a productive research agenda. Healthcare administrators and policy makers in the USA have used this extensive body of work to guide healthcare delivery, financing, and policy reform. Other countries have since followed documenting variations in care, such as the NHS Atlas of Variation in Healthcare and many Canadian provincial atlases and reports, all with the same goals of increasing accountability and improving quality of care (National Health Service *2011*, *2012*; Institute for Clinical Evaluative Sciences *2015*; Manitoba Centre for Health Policy *2015*).

Roadmap of Chapter: Current State of Research and Understanding of Pediatric Medical Practice Variations in Effective Care, Preference-Based Care, and Supply-Based Care

Despite the significant initial work in pediatrics that pioneered our understanding of medical practice variations, the field as it pertains to the care of children and youth has only experienced rapid growth in the past 20 years. The first section of this chapter will describe some of the issues that have hindered progress, including: (1) the ability to adequately delineate appropriate units of analysis or geography reflecting the distinct patterns of healthcare use by children, especially those with more complex problems, (2) the lack of evidence to define quality of care and care-sensitive outcomes, (3) the relative rarity of many conditions making statistical comparisons of outcomes across areas or providers difficult, (4) the relative lack of child health services research capacity and population-based data, and (5) other issues related to child health research in general (the four "D"s, which include Differential epidemiology, Developmental change, Dependency, and Demographics) (Forrest et al. *1997*). The subsequent sections will highlight the current state of research illustrated with examples of pediatric medical practice variations in effective care, preference-based care, and supply-sensitive care. The chapter ends by offering potential future directions in pediatric medical practice variations by addressing methodological limitations, fostering population-based data for monitoring and research, prioritizing areas of research, and continuing to effectively implement evidence into practice and engage in quality improvement to appropriately address variations in pediatric care. Although variations in care may raise concerns about health system performance, such as access, quality, and cost effectiveness of care, this chapter attempts to explain some of the nuance in interpretation of medical practice variations and explain its importance and potential application. The chapter describes innovative ways in which researchers are using variation studies to drive areas for quality improvement as well as the growing numbers of pediatric chronic disease networks across a number of countries, which are embedding variation studies and benchmarking approaches to drive quality improvement and standardization of care.

Pediatric Medical Practice Variations and Child Health Services Research: Special Methodological Considerations

Overview

The primary goal of medical practice variation studies is to measure differences in the behavior and performance of health systems and providers. From this follows the need for attribution of the utilization or outcomes, whenever possible, to the responsible providers. Goodman has outlined two core areas necessary to conduct and interpret studies of variation in health system performance (Goodman *2009*).These include the ability to link populations to their providers and/or geographic "catchment" areas, as well as have important and measureable processes and outcomes that relate to the quality of healthcare to enable judgments around rates of outcomes or care that are meaningful. Interpreting medical practice variation studies also requires an understanding of the term "unwarranted variation." Truly unwarranted variation occurs when the quality, appropriateness, and efficiency of healthcare is the reason for observed differences in utilization and outcomes. Variations are not always unwarranted. Many other factors may contribute to variations in rates of care and outcomes. For example, baseline characteristics and disease risks differ across populations, and should be taken into account when analyzing variations data. Other factors, such as family or child preferences, may contribute to variations in care that are not necessarily unwarranted (Goodman *2009*).

For some time, the study of variations in pediatric care, and child health services research in general, has lagged behind its adult counterpart for various reasons, explored in the following sections. These include the differential epidemiology of both disease and related healthcare seeking patterns, which pose the most important challenges for the study of pediatric care variations as well as a dearth of population-based data and child health services research capacity (Forrest et al. *1997*; Zylke et al. *2012*). Without the ability to understand variations in pediatric care and conduct robust health system performance evaluations, the child health agenda has arguably had less priority and presence in policies and debates around healthcare system reforms.

Challenges in Defining the Unit of Analysis That Properly Reflects Patterns of Healthcare Use by Children

The complex ecology of child healthcare poses a challenge for defining the unit of analysis in variations studies. Depending on the condition, a combination of providers may be implicated in care, including physicians (pediatricians, general physician, pediatric and adult subspecialists), nurses, and allied health professionals (such as occupational therapists and physiotherapists), located in private offices, community settings, and hospitals. Children may receive care in facilities specific to children and may go out of their geographic location to seek specialized care, for example in a pediatric hospital.

Patterns of care may also vary by health systems, as illustrated in studies of primary care in children (Kuo et al. *2006*). In the US, pediatricians provide the majority of primary care and so comparisons across practices are possible where data is available (Shipman et al. *2011*). In other countries such as Canada and the United Kingdom, care is largely provided by general practitioners, and often patient

panels are small making comparisons across providers difficult. Further complicating the study of primary care variations, in countries such as Canada and such as those in Scandinavia, children may have multiple providers and settings for the different components of care (e.g., immunizations by public health nurses, well-child visits by physicians or child health specialists, and early childhood programs based in different community locations) (Kuo et al. *2006*).

Pediatric-specific healthcare resources may have a unique geographical distribution. For children requiring more specialized care, relevant geographic catchment areas such as hospital service areas often differ from those for adults, for both medical and surgical care (Guagliardo et al. *2004*; Goodman et al. *2013*). This is especially the case for an emerging group of children with complex medical conditions. These children represent less than 1 % of the child population but use approximately one-third of total pediatric care expenditures in the USA and Canada (Feudtner et al. *2000*, *2014*; Berry et al. *2014*; Cohen et al. *2012*). They rely on multiple specialists and other services such as home care and it is clear that relevant health outcomes relate to how well this care is coordinated across providers. The implications for pediatric variations studies means that defining a suitable locus of care as the unit of analysis is challenging. The small numbers of these children make comparisons by usual geographic catchment areas such as hospital service areas difficult and arguably not meaningful given their reliance on highly specialized care. Although US policy reforms such as accountable care organizations may provide an appropriate administrative unit of care that crosses primary, specialty, and hospital care it is unclear how these will play out with respect to children (Homer and Patel *2013*).

Lack of Evidence to Support Quality of Care and Health Systems Performance Measurement in Rare Childhood Diseases and Healthy Children

With less research evidence to support pediatric medical practice, defining what is truly unwarranted in practice variations is often difficult. Most childhood diseases are rare, as are important outcomes such as mortality, which has had an impact on the ability to produce gold standard evidence from adequately powered randomized controlled trials to guide practice and define high quality care (Cohen et al. *2007*, *2010*; Martinez-Castaldi et al. *2008*). This has meant that research endeavors to define evidence-based processes and outcomes of care for defining health system performance have had to rely heavily on expert panel consensus methods (Agency for Healthcare Research and Quality *2006*; Alessandrini et al. *2011*). While this level of evidence for performance measures that are used predominantly for quality improvement or hypothesis generating research may be sufficient, measures to be used for accountability either through public reporting or payment purposes require a more rigorous evidence base. Furthermore, outcome measures used to compare providers require risk adjustment. The level of sophistication of risk adjustment methods for children, especially those with complex problems lags far behind work in adults. Measures of hospital readmissions in children is a case in point (Nakamura et al. *2014*). Recent federal funding in the USA for centers of excellence in pediatric quality measurement will help to develop more valid health system measures and risk adjustment tools, including those related to readmissions and care for medically complex children (Nakamura et al. *2014*; Bardach et al. *2010*; Agency for Healthcare Research and Quality *2012*).

The limited evidence base for pediatric practice is not solely a function of small numbers. Whereas most children receive healthcare in the primary care setting, there is also a dearth of evidence to support practice for routine and preventive care. Most of the evidence is low to moderate quality or consensus-based in terms of what topics should be delivered and how to best to counsel on these topics during well-child primary care visits. Guidelines exist (for example, from the United States

Preventive Task Force, Canadian Task Force on Preventive Health Care, American Academy of Pediatrics, Canada Pediatric Society) but in contrast to recommendations for adults, the evidence is not as robust and there are fewer comparative effectiveness studies to support the implementation of the evidence (Melnyk et al. *2012*; Moyer and Butler *2004*). For example, the American Academy of Pediatrics supports over 162 discrete pieces of health directives to be discussed with parents during visits, such as counseling on behavior, nutrition, safety, and screening for social and medical risks. Meanwhile there is little evidence on the efficacy of this counseling in improving child health outcomes (Belamarich et al. *2006*). Given that it is virtually impossible to deliver all the recommended advice within an office minute averaging less than 20 minutes, practice variations are inevitably observed, and it difficult to make clinically or policy relevant judgments on these variations (Halfon et al. *2011*). Albeit, the lack of evidence to guide current primary care practice, there are primary care measures that have been used in the USA and more widely to report on access, technical quality, and appropriateness of pediatric primary care (Agency for Healthcare Research and Quality *2006*; National Committee for Quality Assurance *2015*).

Challenges in Comparing Small Numbers in Pediatric Hospital Care

Small numbers of children requiring hospital care has important implications for variation studies focused on this sector of care. The example of readmissions, a current policy reform focus both in the US and the UK illustrates the difficulty in studying variations in hospital care for children even when outcomes are relevant for children across multiple disease groups (Affordable Care Act *2010*; Kocher and Adashi *2011*; McMorrow *2010*; Department of Health *2013*). A US study examining variation in hospital readmissions for seven common pediatric conditions using large population datasets linking 958 hospitals within six states was unable to classify high- or low- performers, due to overall low hospital volumes (Bardach et al. *2013*). A Canadian report showed similar results, with the majority of community hospitals having volumes of pediatric admissions too small to allow for statistical comparisons of even all-cause 3-year readmission rates across hospitals (Corallo et al. *2012*). The same has been true for studies of other cross-cutting inpatient outcomes such as patient safety measures (Bardach et al. *2010*).

Challenges in Population-Based Data and Research Capacity

Traditionally, most jurisdictions have not had the combination of robust data and health services research capacity to conduct population-based pediatric variations studies. In the USA where there have been longstanding and well-funded training programs for health services research such as the Robert Wood Johnston Foundation and a number of fellowship programs in academic children's hospitals there is a comparatively strong pediatric health services research community. However, in the USA there has been relatively little available population-based health administrative or other data to conduct variations studies. Some data such as the Health Care Cost and Utilization Project Kids Inpatient Database is nationally representative but does not have geographic identifiers and only limited data on providers. Medicaid data available for research sometimes includes geographic identifiers and healthcare services outside of only hospital care, but is not representative of the population of children or providers as a whole, and longitudinal studies are hampered by turnover in enrolment. Many US pediatric hospitals have been collaborating to make their data available to researchers but these data are limited to care by these providers only (Srivastava and Landrigan *2012*). Comprehensive US data on populations and providers does exist from some healthcare organizations such as Kaiser Permanente, but does not allow study across different models of care, arguably the

main purpose of variations study. More recently in the USA, the creation of All Payer Claims Databases by a number of states is a promising development to enable research on children across insurance schemes. These are comprehensive data on all sectors of healthcare including pharmaceuticals with geographic identifiers for both the child and provider. A recent comprehensive atlas on variations in care for children in Northern New England illustrates the potential for these data to inform care and policy (Goodman et al. *2013*). Finally, in the USA and elsewhere a number of disease and care networks have developed registries which include data to measure different aspects of care (see section on Reducing Variations in Effective Care Through Networks).

Outside of the US, countries with universal healthcare coverage such as in Canada and the Nordic countries, have research access to population-based health administrative data, that is longitudinal and represents all publicly funded healthcare services and providers (Institute for Clinical Evaluative Sciences *2015*; Manitoba Centre for Health Policy *2015*; Population Data BC *2015*; Brownell et al. *2002*; Kocevar et al. *2004*). However, in part because of funding models often data are not sufficiently detailed to study technical aspects of care. For example, global funding of hospitals means that there is very little data on specific processes of care such as medication use or diagnostic imaging. Furthermore, outside of the USA there is very limited child health services research capacity to use these available data. For example, the most recent international review of the Canadian Institutes for Health Research (the main federal health research funding agency) cited the lack of maternal and child health services research capacity as an important gap (Canadian Institutes of Health Research *2011*). In the UK, recent big data initiatives to link and make health administrative data from both hospitals and primary care practices more available in combination with dedicated epidemiology teams for maternal and child health research at a number of the Farr centers bodes well for studies of variation in pediatric healthcare performance in England and the rest of the UK (The Farr Institute of Health Informatics Research *2015*).

Other Challenges in Child Health Research

The 4 Ds (Differential epidemiology, Developmental change, Dependency, and Demographics) of child health research also apply to the study of variations. The previous sections have already addressed many issues related to the epidemiology of childhood diseases as it pertains to the study of variations. Developmental change, the fact that each age is associated with a different stage of development (physical, psychological, emotional, and social), has direct implications on study variables and outcomes. Sample sizes need to be large enough to adequately represent each age and stage of development. Observed variations in practice may also be due to the dependency of the child on the parent or caregiver to access and/or receive care, and not as a direct result of the performance of the health system or healthcare providers. Lastly, social determinants of health (demographics) such as family income and caregiver education, are intimately related to the epidemiology, risk factors, and outcomes of child health, and must be considered as important confounders in pediatric medical practice variation studies. To illustrate, in Northern New England (Maine, New Hampshire, and Vermont), hospital service areas of high poverty had lower rates for most measures of effective care (such as access to primary care and well-child care) (Goodman et al. *2013*). Whereas in the US race, ethnicity and insurance status are recorded in many health administrative datasets, in other countries such as Canada, often only census based area level socio-economic data are available. While this is not an issue exclusive to research on children, arguably the relevant socio-economic data related to child health, such as caregiver education and literacy are not routinely available in population-based datasets that would be appropriate for studies of variations in pediatric care.

Pediatric Medical Practice Variations in Effective Care

Overview

Interpreting variations in effective care requires that there is evidence to support a technical quality or standard of care, or that the benefits of an intervention far outweigh any potential harm. The right rate of care is established, and unwarranted variation occurs when there is underuse. The provision of immunizations is one such classic example. However, many areas of pediatric care, including important ones such as primary and preventive care, lack evidence and therefore do not lend themselves to the study and understanding of variations in effective care (Melnyk et al. *2012*; Moyer and Butler *2004*; Gill et al. *2011*). Despite the absence of solid evidence, studies on variations, and particularly those conducted through collaborating networks of care, can lead to help establish benchmarks for potential "right" rates of care and identify priority areas to study and target quality improvement efforts.

Immunizations: An Evidence-Based Performance Measure Where the Right Care is Established

Childhood immunizations are the classic example for which technical quality is established and the right rate of care is known. Immunizations are deemed one of the greatest achievements in public health in the twentieth century. It is an intervention that has saved millions of lives, eradicated diseases such as smallpox, and decreased morbidity of important diseases such as polio, pertussis, *Haemophilus influenza* type b infections, and measles (Centers for Disease Control and Prevention *1999*). When rates of immunizations drop, outbreaks may occur. Childhood immunization rates for these vaccine-preventable conditions are established indicators of primary care and public health systems performance, where anything less than 100 % represents a suboptimal performance (Becker et al. *2006*).

In the UK, the *Atlas of Variation in Healthcare for Children and Young People* has documented child health indicators, including rates of immunization. For routine vaccinations against diphtheria, tetanus, pertussis, polio and *Haemophilus influenza* type b in children at 2 years old, they reported a rate of 85.3–99.2 % (1.2-fold variation) between primary care trusts (local administrative bodies for primary and community health and social services) in England, which meant an 18-fold variation (0.8–14.7 %) in those who did **not** receive a full course of these vaccinations. Similarly, the percentage of children at 2 years old with complete routine vaccinations against pneumococcal disease ranged from 63.9 % to 97.4 % (1.5-fold variation) and from 73.0 % to 96.7 % (1.3-fold variation) for measles, mumps and rubella (National Health Service *2012*).

Monitoring variations in immunizations within jurisdictions may improve system performance especially if these data systems are connected to providers and can be used for audit and feedback. Some countries have succeeded in establishing registries to keep track of immunization data (including Australia since 1996, and more recently, the UK, New Zealand, and Denmark), which have helped them to achieve high rates of immunization coverage (Guttmann et al. *2011*). However, recent recurrences of measles outbreaks in the North America have highlighted that even with the best of evidence to support practice many challenges in reducing variations in effective care exist. In the case of immunizations, this relates predominantly to parental decisions to not vaccinate, but also barriers

related to lack of recall and reminder systems. In Canada, both the lack of immunization registries as well as the various providers responsible for immunizations (including public health, primary care, and schools) has made documenting variation in immunization rates as well as providing feedback and audit to providers difficult (Guttmann et al. *2011*).

Asthma and Type I Diabetes: Examples of Common Childhood Conditions With Documented Variations in Effective Care

Childhood asthma is the most common chronic disease in childhood associated with high healthcare utilization and costs, and a number of treatment modalities that are effective making it an ideal area for the study of variations and health system performance (Bahadori et al. *2009*; Moorman et al. *2012*; To et al. *2001*). Most pediatric asthma variation studies have focused on acute care (emergency visits and admissions), where large health administrative datasets are often available (Bardach et al. *2013*; Li et al. *2012*; Parikh et al. *2014*). For example, studies have shown variation across hospital emergency departments in the use of corticosteroids during an acute asthma attack, which is an evidence-supported effective practice (Kharbanda et al. *2013*; Lougheed et al. *2009*). However, recent US work on 30 hospitals assessing the first Joint Commission evidence-based measures applicable to hospitalized children, the Children's Asthma Care measure set (use of relievers, systemic corticosteroids and discharge with a home management plan), reported no variation in the medication measures with all hospitals at high levels of compliance. Although there was significant variation in the use of home management care plans, this was not associated with subsequent acute care for asthma exacerbations (Morse et al. *2011*).

Another common childhood chronic disease is diabetes, for which good control of blood glucose levels can prevent serious complications such as diabetic ketoacidosis. Rates of hospitalizations for diabetic ketoacidosis should be largely preventable with effective care, and as such are a quality indicator in many jurisdictions (Agency for Healthcare Research and Quality *2006*; National Paediatric Diabetes Audit *2013*). In the UK, there was a sevenfold variation (6.4–46.7 %) across primary health trusts in the percentage of children aged 0–15 years previously diagnosed with diabetes who were hospitalized for diabetic ketoacidosis (National Health Service *2012*). Older Canadian research reported over twofold variation in admissions for diabetic ketoacidosis among children with diabetes across Ontario District Health Councils (To et al. *2003*). In the USA, there have been few population-based studies of children with diabetes and their patterns of acute care use, but one recent Pediatric Research in Inpatient Settings Network (PRIS) study suggested significant variation in costs and readmissions for children admitted for diabetes ketoacidosis (Tieder et al. *2013*).

When Evidence Lacks to Support Effective Care, Studies on Pediatric Practice Variations may Lead to Prioritization of Research Areas and Quality Improvement Efforts

Identifying areas of high practice variation may point to recommendations where low-quality or consensus evidence is inadequate to support practice, prompt further research into the benefits as well as harms of healthcare interventions, and lead to quality improvement efforts. In the hospital setting, researchers identified 50 pediatric conditions with the highest prevalence, cost, and variations in resource utilization using administrative and billing data from the Pediatric Health Information System, which comprises over 40 free standing children's hospitals in the USA (Keren et al. *2012*).

Some of these top issues were related to the premature infant, common medical admissions (pneumonia, asthma, bronchiolitis), and management of common surgical procedures (hypertrophy of adenoids and tonsils, congenital heart disease, otitis media, appendicitis). Similarly in primary care practice, a survey of pediatricians in the Pediatric Research in Office Settings (PROS) research network identified the need for evidence in well-child care and anticipatory guidance (preventive care through education and counseling on topics related to health and development in children) (Chien et al. *2006*). Indeed, studies have documented a wide variation in these areas, which are key components of pediatric primary care (Halfon et al. *2011*).

Community-acquired pediatric pneumonia is an example of how variation studies have identified a focus for quality improvement. Although guidelines exist for the diagnosis and management, there is a paucity of evidence to support the use of diagnostic tests such as C-reactive protein and white blood cell count, which have led to several studies documenting significant variation in their use amongst emergency departments. Less care has not shown to be worse care: emergency departments that do less testing do not necessarily have more emergency revisit rates (Parikh et al. *2014*; Florin et al. *2013*; Leyenaar et al. *2014*). Therefore, carefully designed quality improvement interventions could target the reduction of laboratory investigations for uncomplicated pediatric pneumonia, without increasing adverse outcomes.

Where Evidence is Lacking, Studies on Pediatric Practice Variations can be Used to Establish Benchmarks for Health System Performance

In the case of childhood asthma, when evidence-based practices are available, studies on practice variations help in the design of interventions to target the low performers not adhering to established quality measures (as illustrated above). But for areas of care for which the evidence is low or consensus-based, such as the use of chest radiographs in acute asthma, the study of variations may help establish benchmarks (Parikh et al. *2014*). Radiographs may be unnecessary, contribute to costs, decrease the efficiency of an emergency department or service, and exposes the child to the ill effects of radiation. Since the rates of chest radiograph use are lower in pediatric-focused emergency departments in the USA and Canada, these rates could be used as an initial benchmark for hospitals to target when the right rate cannot be established with robust evidence to support effective care (Guttmann et al. *2013*; Knapp et al. *2013*).

Reducing Variations in Effective Care Through Networks

Many promising networks of care have developed disease registries, care protocols, and in some cases quality improvement capacity to use principles of variations studies to improve patient outcomes. The best prototype in terms of imbedding research protocols to test new therapies is the Children's Oncology Group, a clinical research group involving over 200 hospitals from around the world. COG has been able to standardize care and improve outcomes for childhood cancer at a rate far more accelerated compared to adults. Whereas previously, cures did not exist for some cancers, the current combined survival rate of all childhood cancers is approximately 80 % (O'Leary et al. *2008*). However, to date this network has not measured processes or outcomes of care at center levels to benchmark or reduce variations in care that might not be related to treatment protocols.

There are notable examples of pediatric disease and care networks, which have used the paradigm of measurement of variations and benchmarking of care performance to drive quality improvement.

Some have adopted public reporting to increase transparency and accountability. The US network of cystic fibrosis centers uses a national registry and public reporting of variations in quality of care metrics including outcomes by center to drive both quality improvement and accountability (Cystic Fibrosis Foundation *2015*). Internationally, 20 out of 27 European Union countries have pediatric diabetes registries, and the Nordic countries as well as England and Wales have published their experience using performance data and benchmarks to improve care (and in the case of England and Wales publish results by region) (National Paediatric Diabetes Audit *2013*; Cinek et al. *2012*). Neonatal networks such as the Vermont Oxford Collaborative, the California Perinatal Quality Care Collaborative, and the Canadian Neonatal Network have also published promising results of efforts to measure, benchmark and reduce variations in care and outcomes such as hospital acquired infections for preterm infants although the performance measures by center are not publicly reported (Horbar et al. *2001*; Kilbride et al. *2003*; Lee et al. *2000*). More recently, an international neonatal network (the International Network for Evaluating Outcomes of very low birth weight, very preterm neonates; iNeo) was created, assembling 251 neonatal intensive care units across eight neonatal networks in nine countries caring for 23,000 to 24,000 very low birth weight newborns yearly. Each site has the mandate of collecting data, identifying variations in care, benchmarking performance, and engaging in quality improvement (Shah et al. *2014*). Many other examples of care networks across pediatric conditions such as inflammatory bowel and care sectors such as pediatric intensive and emergency care are developing (Crandall et al. *2011*; Billett et al. *2013*; Klassen et al. *2010*). Translating Emergency Knowledge to Kids (TREKK) is a network in Canada working on creating tools to increase the uptake of evidence for the acute management of common acute conditions such as asthma and developing the best strategies for effective implementation (Jabbour et al. *2013*). Although the evidence-base to define effective care measures, funding of functional registries and quality improvement capacity to act on variation data remain a challenge, these care networks hold great promise for defining, measuring and improving standards of care for many groups of children.

Pediatric Medical Practice Variations in Preference-Based Care

Overview

Preference-based variations in care occur when there are several care options, each with their own benefits and tradeoffs but none that have substantial benefit without compromise. Clinicians and families often assign different values to outcomes, and the evidence to support the probabilities of outcomes may be lacking. Preference-based variations in care often reflect the practice styles and opinions of the healthcare professionals. Unwarranted variations may occur when families and children are not fully informed of and/or do not fully participate in the decisions in care. Although the concept originated from non-pediatric studies on benign prostatic hyperplasia, there are numerous examples of variations in preference-based care in pediatric medicine due to the limited evidence supporting the management of many childhood conditions and complexities involved in deciding on treatment (Wennberg et al. *1988*). The use of shared decision making and decision aids shows promise in reducing unwarranted pediatric practice variations in preference-based care.

The Balance of Benefits and Tradeoffs in Preference-Based Care: The Example of Otitis Media

The current understanding and management of otitis media, a middle ear infection common in childhood, illustrates some of the considerations in preference-based care. Treatment options include antibiotics, delayed use of antibiotics, or no antibiotics at all. Although the use of antibiotics may reduce the duration of symptoms such as ear pain, symptoms resolve in most children spontaneously over time. In a Cochrane review of randomized controlled trials examining the effects of antibiotics for otitis media in children, the authors concluded several benefits of antibiotic use. These included the following numbers needed to treat for an additional beneficial outcome: 20 to prevent one child from having ear pain between 2 and 7 days, 33 for a tympanic membrane perforation, and 11 for a contralateral otitis media infection. However, the number needed to treat for an additional harm was 14 for adverse events (such as vomiting, diarrhea, and rash) (Venekamp et al. *2013*). Given this balance of outcomes between treating and not treating and the natural evolution of the disease, variations in practice arise when providers and parents value options differently.

Variations in Preference-Based Care Illustrated by Middle ear Surgery in Childhood

Myringotomy (incision of the ear drum) with the insertion of tympanostomy tubes is a treatment option for otitis media, usually reserved for persistent treatment failure or recurrent infections. Along with adenotonsillectomy in children, the placement of tympanostomy tubes is one of the most common surgical procedures for which small area variation has been documented. A study in Canada using population-based data demonstrated a tenfold variation in age- and sex- standardized surgical rates across regions. After adjusting for physician and population characteristics, it was concluded that the opinion of the primary care physician, and specifically their enthusiasm and subsequent referral to surgeons for tympanostomy tubes, was a dominant determinant for increased procedure rates. It is unclear from this study the extent to which shared-decision making was applied but it is likely that the preference of the physician was an important factor in the parents' final decision (Coyte et al. *2001*).

Shared Decision Making and the use of Decision Aids to Reduce Unwarranted Variation in Preference-Based Care

Variations in preference-sensitive care are warranted when families and clinicians participate in selecting the management plan together through shared decision making. In shared decision making, the healthcare providers and families discuss the different options, including the associated risks and benefits, and taking into account the families' values to come together to a decision. Some topics in pediatric medicine amenable to shared decision making include the management of otitis media, acne, enuresis, behavior problems (such as attention deficit and hyperactivity disorder), idiopathic thrombocytopenic purpura and interventions such as circumcisions and birth control, as well as interventions for children with medical complexity such as the use of gastrostomy-tube feeding (Fiks and Jimenez *2010*; Beck et al. *2014*). In the USA, the Institute of Medicine has endorsed research comparing the effectiveness of shared decision making and it is written in healthcare policy (the 2010 Patient Protection and Affordable Care Act) as a provision for use in clinical settings to improve care and reduce costs (Affordable Care Act *2010*; Institute of Medicine (U.S.) *2009*).

The implementation of shared decision making may involve the use of decision aids. These are tools, which clearly delineate the decision, options, outcomes, and issues that need to be considered (such as preferences and values) to arrive to a management plan. The purpose of decision aids is to assist in one or all of the components of shared decision making: (1) help inform patients and families on the

outcomes associated with care options (benefits, tradeoffs, and probabilities); (2) clarify patient treatment/life goals and values, and (3) invite and involve them to express their preferences in a joint process (with the clinician) in reaching a decision right for them. Decision aids may increase the family's involvement in the decision and consequently, lead to more informed decisions and reduce the use of treatments that families do not value (O'Connor et al. *2009*). In Canada, the Children's Hospital of Eastern Ontario hosts a website with an inventory of pediatric decision aids, for specific conditions as well as a generic tool that can be applied to any condition (the Ottawa Family Decision Guide developed by the Ottawa Hospital Research Institute) (Children's Hospital of Eastern Ontario *2015*). The decision aids may vary in their quality and are only beginning to expand for pediatric-specific health issues. Even with the use of decision aids, potential difficulties in implementing shared decision making include differing levels of parental understanding of the issues being considered, paternalism of the healthcare provider, and ensuring adequate involvement of the child in making the decision, when applicable (Fiks and Jimenez *2010*).

Shared Decision Making in Pediatrics: Children With Chronic Conditions

Shared decision making is one of the core attributes of the primary care medical home (a model or approach to delivery of care that is patient-centerd, comprehensive, coordinated, and accessible) (American Academy of Pediatrics *2002*). In children with chronic diseases who have high rates of hospitalizations, emergency department visits, and increased health system costs, shared decision making shows promise in improving these outcomes (Fiks et al. *2012*). For children with medical complexity, who often suffer from multiple chronic diseases where management goals may be directed to improving quality rather than quantity of life and where issues of caregiver burden are substantial, shared decision making may be especially important. One particular topic relevant to children with medical complexity is the treatment of feeding intolerance with gastrostomy tubes. Families may be faced with the option of choosing between different surgeries (e.g., option of a fundoplication) and tubes (that go either into the stomach or jejunum). The decision is multifaceted and may lead to significant variations in practice – healthcare providers may prefer one type of intervention, especially in the case where surgeons are more experienced in one type of surgery, while parents may differ in which outcomes of care they value that may include health services use, complications, quality of life, and personal financial impact (Mahant et al. *2011*). In fact, a funded trial to compare outcomes of gastrostomy tubes with fundoplication versus gastrojejunal tubes was unsuccessful in enrolling participants because of parental and surgeon preferences. In deciding on the "right" and acceptable care for a family and child, shared decision making and decision aids can help balance all the considerations required for an informed treatment plan.

Pediatric Medical Practice Variations in Supply-Sensitive Care

Overview

Variations in supply-sensitive care occur when utilization of services are sensitive to the healthcare resources of the system, such as hospital beds, diagnostic imaging capacity, and physician/healthcare providers. This type of variation mainly occurs around "discretionary" care, where there is little

evidence to support the right rate of care, several alternatives may be available, and multiple factors play into the final decision for care. Where outcomes are more or less equivalent, the lowest rate of service use would be the targeted right rate while higher rates may represent overuse of care. There are few studies examining this category of variations in children's care.

The Geographic Maldistribution of Pediatric Healthcare Supply Compared to Child Health Needs

From what little data is available, it is clear that variation in physician supply and hospital resources (e.g., beds) is not solely related to child health need. A US study on neonatal intensive care capacity demonstrated that there was no statistically significant association between area-level need (low birth weight rates) and supply of neonatologists or neonatal intensive care beds (Goodman et al. *2001*). Another US study using national pediatric workforce data for primary care service areas between 1996 and 2006 demonstrated a geographic maldistribution – almost 20 % of the child population in the USA (15 million children) lived in areas where there were less than 720 children per child physician (about 141 child physicians per 100,000 children) and another 20 % of the child population lived in areas where there were more than 4,400 children per child physician (about 22 child physicians per 100,000 children), while about a million children lived in areas with no local child physicians (Shipman et al. *2011*). The recent Dartmouth Atlas underscored similar patterns of geographic maldistribution of child health physicians, with almost tenfold differences across communities and no relationship to other measures of child health need (Goodman et al. *2013*). A provincial mental health scorecard for children and youth pointed to the significant geographic mismatch between mental health needs and child psychiatrist supply in Ontario, Canada. Even including telehealth, rates of child psychiatrist visits were significantly lower in health regions with fewer psychiatrists but more child mental health needs as measured by rates of suicide and acute care use for mental health problems and addictions (MHASEF Research Team *2015*).

The Influence of Healthcare Supply on Utilization Rates and Appropriateness of Care: Examples in Primary Care, Asthma Hospitalizations, and Diagnostic Imaging

US and Canadian studies have documented the association of low physician supply and measures of potentially preventable emergency department care and admissions for ambulatory care sensitive conditions (Laditka et al. *2005*; Guttmann et al. *2010*). At the same time, Canadian children living in areas with relatively higher physician supply had rates of potentially inappropriate primary care such as follow-up visits for simple viral infections and repeated visits for acne (Guttmann et al. *2010*). Very few studies in children have defined care measures related to physician oversupply. Through the Choosing Wisely campaign, which promotes physicians and patients to engage in conversations about evidence-based care, other measures of overuse in pediatrics are being defined (Choosing wisely *2015*). However, it is unknown whether these measures reflect overcapacity in a health system and/or inadequate dissemination of evidence-based practice.

Hospitalization rates in certain childhood conditions demonstrate how healthcare supply can influence utilization. Where conditions require definitive admission for treatment and observation, such as the case of bacterial meningitis, variation in hospitalization rates are often low between hospitals or regions. But where the diagnosis may be uncertain and/or do not need specific inpatient medical treatment (decisions may be discretionary), such as the case of viral meningitis, the variation in rates

are often high. Pediatric asthma is a good illustration of this point. When an asthma exacerbation is not severe, it may be managed in the physician's office, emergency department, or the inpatient setting. A longer period of observation and management in the outpatient setting could potentially prevent an admission. Although clinicians consider several clinical, parental, and social parameters in deciding on an admission an older US study examining hospital admissions for asthma in Maine, New Hampshire, and Vermont between 1985 and 1989 concluded that children living in areas of high per capita bed supply (4.0/1,000) had 9 % more admissions than those living in areas of low per capita bed supply (1.9/1,000) (Goodman et al. *1994*). There has been little other work exploring variations in pediatric admissions and bed supply.

More recently US studies have focused on rates of diagnostic imaging, especially computed tomography (CT) use in children given both the relatively high rates of use compared with other jurisdictions and the increased lifetime risk of cancer from radiation compared to adults (Berdahl et al. *2013*; Miglioretti et al. *2013*). Studies in adults and children have consistently demonstrated that the more CT scans are available, the higher the CT use (The Dartmouth atlas of health care *2015*; Berdahl et al. *2013*). The Dartmouth Atlas of Children's Health Care in Northern New England reported a threefold variation in rates (4.0–15.4 scans per 1,000 children) of CT scan use for head and abdominal imaging across hospital service areas. In this latter study, it is likely that variations in evidence-based and preference-based care also contributed towards these variations in CT use, since hospital service areas with children's hospitals used at least 20 % fewer scans (Goodman et al. *2013*).

Future Directions

Summary

The study of pediatric medical practice variations has a long history stemming from Glover's report in 1938 but still has some distance to go. There needs to be continued momentum to address the methodological limitations in child health services and practice variations research, create informative and linkable data across settings, prioritize areas of research, advance implementation science to translate evidence into practice, and improve on methods of measurement and risk adjustment to support policies to improve accountability such as public reporting. The ultimate goal is not to eliminate variations but to use this tool of study to describe the needs, preferences, and performance of child healthcare and services, from which children, families, clinicians, and health administrators can decide on the best solutions to improve child health outcomes.

Efforts to Improve Child Health Research and Develop Evidence-Based Outcome Measures

Continuing efforts are being made to improve child health research, such as those of the Standards for Research in (StaR) Child Health (Hartling et al. *2012*). Established in 2009, StaR is comprised of an international group of researchers, methodologists, practitioners, regulators, and journal editors with a mission "to improve the design, conduct, and reporting of pediatric research through the development and dissemination of evidence-based standards." They have published priority areas of research as well as recommendations on research design, conduct, and reporting in pediatrics.

Recent US federal investments focused on the development of pediatric healthcare performance measures to drive quality improvement and accountability will no doubt move the field forward (Agency for Healthcare Research and Quality *2012*). The development of a number of pediatric research networks, many of which are addressing the dearth of relevant data through disease registries is also promising. This includes many sectors of care including emergency department care (with the establishment of several international collaborations in the USA, Canada, Australia, New Zealand, Europe, and the Middle East), as well as inpatient and outpatient care (through North American groups such as Pediatric Research in Inpatient Settings, (PRIS) Pediatric Research in Office Settings (PROS), and TargetKids) (Srivastava and Landrigan *2012*; Klassen et al. *2010*; Wasserman et al. *1998*; Morinis et al. *2012*). These international examples of condition and disease-based networks are advancing promising applied research and data-driven approaches to quality improvement.

Future Research Directions

The study of practice variations can inform conceptual frameworks that map out priority areas for child health and health services research, and ultimately bring about a positive influence on clinical care, performance, and policy. We have described ongoing work to improve the evidence to guide pediatric care, a growing emphasis on the development of pediatric performance measurement, and increasing numbers of care based networks with quality improvement capacity. While these developments will help to reduce unwarranted variations and improve care for children with a number of diseases, challenges remain. Children without formal networks of care may fall between the cracks. Children with multiple and complex chronic conditions, who represent the group with the highest healthcare needs, do not necessarily fit into any one disease category or network of care. Important areas for research include the development of measures that reflect effective care including patient and family centered outcomes and operationalizing and measuring integrated care systems to better reflect changing systems of care and accountability. More fundamentally, variation studies in their most pure form focus on populations unrelated to care-seeking behavior. A majority of pediatric variations studies have focused on hospitalized children (and often only those in pediatric hospitals). Clearly, there are many important research questions around variations in effective hospital care for children, but understanding variations in the trajectories of care and outcomes for children with chronic conditions are important. Although many disease networks have registries which capture all children irrespective of being hospitalized, voluntary enrollment in these networks may mean participating providers are more likely to be interested in measurement and quality improvement. This limits the generalizability and potentially the policy relevance of the research and may represent an important equity issue.

While the rarity of many childhood diseases and the small number of specialized providers has provided a challenge in terms of being a focus of healthcare reform it has arguably allowed quality improvement efforts to grow more organically and with documented success around improvement of some child outcomes. However, further research should ensure that these efforts do not allow for greater inequities in outcomes based on geography or family socioeconomics. Research that is population-based and at arms length from networks of care is critical. Finally, while the larger policy context of aligning funding with quality and improving transparency through public reporting and benchmarking may ultimately drive improvements in pediatric care important challenges remain. Researchers will need to continue to develop valid performance measures and risk adjustment tools to allow meaningful measurement and limit unintended consequences. Developing data and research infrastructures that enable both locally relevant work but also cross-jurisdictional studies, in particular

across different healthcare systems that use different policy levers to drive healthcare quality, will also be important.

References

Agency for Healthcare Research and Quality. Pediatric quality measures program (PQMP) centers of excellent grant awards. Rockville: Agency for Healthcare Research and Quality; 2012.

Agency for Healthcare Research and Quality. Measures of pediatric health care quality based on hospital administrative data: the pediatric quality indicators. Rockville: AHRQ; 2006. http://www.qualityindicators.ahrq.gov/modules/pdi_resources.aspx

Alessandrini E, Varadarajan K, Alpern ER, et al. Emergency department quality: an analysis of existing pediatric measures. Acad Emerg Med. 2011;18:519–26.
CrossRef PubMed

American Academy of Pediatrics. The medical home. Pediatrics. 2002;110:184–6.
CrossRef

Bahadori K, Doyle-Waters MM, Marra C, et al. Economic burden of asthma: a systematic review. BMC Pulm Med. 2009;9:24.
PubMedCentral CrossRef PubMed

Bardach NS, Chien AT, Dudley RA. Small numbers limit the use of the inpatient pediatric quality indicators for hospital comparison. Acad Pediatr. 2010;10:266–73.
PubMedCentral CrossRef PubMed

Bardach NS, Vittinghoff E, Asteria-Penaloza R, et al. Measuring hospital quality using pediatric readmission and revisit rates. Pediatrics. 2013;132:429–36.
PubMedCentral CrossRef PubMed

Beck CE, Boydell KM, Stasiulis E, et al. Shared decision making in the management of children with newly diagnosed immune thrombocytopenia. J Pediatr Hematol Oncol. 2014;36:559–65.
CrossRef PubMed

Becker L, Pickett J, Levine R. Measuring commitment to health: global health indicators working group report. Washington, DC: Center for Global Development; 2006. http://www.cgdev.org/publication/measuring-commitment-health-global-health-indicators-working-group-report

Belamarich PF, Gandica R, Stein RE, Racine AD. Drowning in a sea of advice: pediatricians and American Academy of Pediatrics policy statements. Pediatrics. 2006;118:e964–78.
CrossRef PubMed

Berdahl CT, Vermeulen MJ, Larson DB, Schull MJ. Emergency department computed tomography utilization in the United States and Canada. Ann Emerg Med. 2013;62:486–94.
CrossRef PubMed

Berry JG, Hall M, Neff J, et al. Children with medical complexity and Medicaid: spending and cost savings. Health Aff (Millwood). 2014;33:2199–206.
CrossRef

Billett AL, Colletti RB, Mandel KE, et al. Exemplar pediatric collaborative improvement networks: achieving results. Pediatrics. 2013;131 Suppl 4:S196–203.
CrossRef PubMed

Board of Education. Health of the schoolchild. Annual report of the chief medical officer of the board of education for 1920. London: Board of Education; 1920.

Board of Education. Annual report of the chief medical officer of the board of education for 1931. London: Board of Education; 1931.

Brownell M, Mayer T, Martens PJ, et al. Using a population-based health information system to study child health. Canadian J Publ Health (Revue canadienne de sante publique). 2002;93 Suppl 2:S9–14.

Canadian Institutes of Health Research. International review panel report. Ottawa: Canadian Institutes of Health Research; 2011.

Centers for Disease Control and Prevention. Impact of vaccines universally recommended for children--United States, 1990–1998. MMWR Morb Mortal Wkly Rep. 1999;48:243–8.

Chien A, Coker T, Choi L, et al. What do pediatric primary care providers think are important research questions? A perspective from PROS providers. Ambul Pediatr. 2006;6:352–5.
CrossRef PubMed

Children's Hospital of Eastern Ontario. CHEO family decision services. http://www.cheo.on.ca/en/decisionaids. Accessed 1 Mar 2015.

Choosing wisely. http://www.choosingwisely.org/. Accessed 1 Mar 2015.

Cinek O, Sumnik Z, de Beaufort C, et al. Heterogeneity in the systems of pediatric diabetes care across the European Union. Pediatr Diabetes. 2012;13 Suppl 16:5–14.
CrossRef PubMed

Cohen E, Uleryk E, Jasuja M, Parkin PC. An absence of pediatric randomized controlled trials in general medical journals, 1985–2004. J Clin Epidemiol. 2007;60:118–23.
CrossRef PubMed

Cohen E, Goldman RD, Ragone A, et al. Child vs adult randomized controlled trials in specialist journals: a citation analysis of trends, 1985–2005. Arch Pediatr Adolesc Med. 2010;164:283–8.
CrossRef PubMed

Cohen E, Berry JG, Camacho X, Anderson G, Wodchis W, Guttmann A. Patterns and costs of health care use of children with medical complexity. Pediatrics. 2012;130:e1463–70.
PubMedCentral CrossRef PubMed

Corallo A, Li Q, Wodchis W, Guttman A. For what proportion of Ontario hospitals could a reliable pediatric readmission indicator be produced. Toronto: Institute for Clinical Evaluative Sciences; 2012.

Coyte PC, Croxford R, Asche CV, To T, Feldman W, Friedberg J. Physician and population determinants of rates of middle-ear surgery in Ontario. JAMA. 2001;286:2128–35.
CrossRef PubMed

Crandall W, Kappelman MD, Colletti RB, et al. ImproveCareNow: the development of a pediatric inflammatory bowel disease improvement network. Inflamm Bowel Dis. 2011;17:450–7.
CrossRef PubMed

Cystic Fibrosis Foundation. http://www.cff.org/treatments/CareCenterNetwork/. Accessed 1 Mar 2015.

Department of Health. Payment by results guidance for 2013–2014. Gateway reference 18768. London: Department of Health; 2013.

Feudtner C, Christakis DA, Connell FA. Pediatric deaths attributable to complex chronic conditions: a population-based study of Washington State, 1980–1997. Pediatrics. 2000;106:205–9.
PubMed

Feudtner C, Feinstein JA, Zhong W, Hall M, Dai D. Pediatric complex chronic conditions classification system version 2: updated for ICD-10 and complex medical technology dependence and transplantation. BMC Pediatr. 2014;14:199.
PubMedCentral CrossRef PubMed

Fiks AG, Jimenez ME. The promise of shared decision-making in paediatrics. Acta Paediatr. 2010;99:1464–6.
PubMedCentral CrossRef PubMed

Fiks AG, Mayne S, Localio AR, Alessandrini EA, Guevara JP. Shared decision-making and health care expenditures among children with special health care needs. Pediatrics. 2012;129:99–107.
PubMedCentral CrossRef PubMed

Florin TA, French B, Zorc JJ, Alpern ER, Shah SS. Variation in emergency department diagnostic testing and disposition outcomes in pneumonia. Pediatrics. 2013;132:237–44.
CrossRef PubMed

Forrest CB, Simpson L, Clancy C. Child health services research. Challenges and opportunities. JAMA. 1997;277:1787–93.
CrossRef PubMed

Gill PJ, Wang KY, Mant D, et al. The evidence base for interventions delivered to children in primary care: an overview of cochrane systematic reviews. PLoS One. 2011;6, e23051.
PubMedCentral CrossRef PubMed

Glover JA. The incidence of tonsillectomy in school children: (Section of epidemiology and state medicine). Proc R Soc Med. 1938;31:1219–36.

PubMedCentral PubMed

Goodman DC. Unwarranted variation in pediatric medical care. Pediatr Clin North Am. 2009;56:745–55.
PubMedCentral CrossRef PubMed

Goodman DC, Fisher ES, Gittelsohn A, Chang CH, Fleming C. Why are children hospitalized? The role of non-clinical factors in pediatric hospitalizations. Pediatrics. 1994;93:896–902.
PubMed

Goodman DC, Fisher ES, Little GA, Stukel TA, Chang CH. Are neonatal intensive care resources located according to need? Regional variation in neonatologists, beds, and low birth weight newborns. Pediatrics. 2001;108:426–31.
CrossRef PubMed

Goodman DC, Morden NE, Ralston SL, Chang CH, Parker DM, Weinstein SJ. The Dartmouth Atlas of children's health care in Northern New England. New Hampshire: The Dartmouth Institute for Health Policy & Clinical Practice; 2013. http://www.dartmouthatlas.org/downloads/atlases/NNE_Pediatric_Atlas_121113.pdf

Guagliardo MF, Jablonski KA, Joseph JG, Goodman DC. Do pediatric hospitalizations have a unique geography? BMC Health Serv Res. 2004;4:2.
PubMedCentral CrossRef PubMed

Guttmann A, Shipman SA, Lam K, Goodman DC, Stukel TA. Primary care physician supply and children's health care use, access, and outcomes: findings from Canada. Pediatrics. 2010;125:1119–26.
CrossRef PubMed

Guttmann A, Shulman R, Manuel D. Improving accountability for children's health: immunization registries and public reporting of coverage in Canada. Paediatr Child Health. 2011;16:16–8.
PubMedCentral PubMed

Guttmann A, Weinstein M, Austin PC, Bhamani A, Anderson G. Variability in the emergency department use of discretionary radiographs in children with common respiratory conditions: the mixed effect of access to pediatrician care. CJEM. 2013;15:8–17.
PubMed

Halfon N, Stevens GD, Larson K, Olson LM. Duration of a well-child visit: association with content, family-centeredness, and satisfaction. Pediatrics. 2011;128:657–64.
CrossRef PubMed

Harris B. The health of the schoolchild: a history of the school medical service in England and Wales. Buckingham/Philadelphia: Open University Press; 1995.

Hartling L, Wittmeier KD, Caldwell P, et al. StaR child health: developing evidence-based guidance for the design, conduct, and reporting of pediatric trials. Pediatrics. 2012;129 Suppl 3:S112–7.
CrossRef PubMed

Homer CJ, Patel KK. Accountable care organizations in pediatrics: irrelevant or a game changer for children? JAMA Pediatr. 2013;167:507–8.
CrossRef PubMed

Horbar JD, Rogowski J, Plsek PE, et al. Collaborative quality improvement for neonatal intensive care. NIC/Q Project Investigators of the Vermont Oxford Network. Pediatrics. 2001;107:14–22.
CrossRef PubMed

Institute for Clinical Evaluative Sciences. http://www.ices.on.ca. Accessed 1 Mar 2015.

Institute of Medicine (U.S.). Committee on comparative effectiveness research prioritization., Institute of Medicine (U.S.). Initial national priorities for comparative effectiveness research. Washington, DC: Institute of Medicine of the National Academies; 2009. http://www.iom.edu/Reports/2009/ComparativeEffectivenessResearchPriorities.aspx

Jabbour M, Curran J, Scott SD, et al. Best strategies to implement clinical pathways in an emergency department setting: study protocol for a cluster randomized controlled trial. Implement Sci. 2013;8:55.
PubMedCentral CrossRef PubMed

Keren R, Luan X, Localio R, et al. Prioritization of comparative effectiveness research topics in hospital pediatrics. Arch Pediatr Adolesc Med. 2012;166:1155–64.
CrossRef PubMed

Kharbanda AB, Hall M, Shah SS, et al. Variation in resource utilization across a national sample of pediatric emergency departments. J Pediatr. 2013;163:230–6.
CrossRef PubMed

Kilbride HW, Wirtschafter DD, Powers RJ, Sheehan MB. Implementation of evidence-based potentially better practices to decrease nosocomial infections. Pediatrics. 2003;111:e519–33.
CrossRef PubMed

Klassen TP, Acworth J, Bialy L, et al. Pediatric emergency research networks: a global initiative in pediatric emergency medicine. Pediatr Emerg Care. 2010;26:541–3.
CrossRef PubMed

Knapp JF, Simon SD, Sharma V. Variation and trends in ED use of radiographs for asthma, bronchiolitis, and croup in children. Pediatrics. 2013;132:245–52.
CrossRef PubMed

Kocevar VS, Bisgaard H, Jonsson L, et al. Variations in pediatric asthma hospitalization rates and costs between and within Nordic countries. Chest. 2004;125:1680–4.
CrossRef PubMed

Kocher RP, Adashi EY. Hospital readmissions and the Affordable Care Act: paying for coordinated quality care. JAMA. 2011;306:1794–5.
CrossRef PubMed

Kuo AA, Inkelas M, Lotstein DS, Samson KM, Schor EL, Halfon N. Rethinking well-child care in the United States: an international comparison. Pediatrics. 2006;118:1692–702.
CrossRef PubMed

Laditka JN, Laditka SB, Probst JC. More may be better: evidence of a negative relationship between physician supply and hospitalization for ambulatory care sensitive conditions. Health Serv Res. 2005;40:1148–66.
PubMedCentral CrossRef PubMed

Lee SK, McMillan DD, Ohlsson A, et al. Variations in practice and outcomes in the Canadian NICU network: 1996–1997. Pediatrics. 2000;106:1070–9.
CrossRef PubMed

Leyenaar JK, Lagu T, Shieh MS, Pekow PS, Lindenauer PK. Variation in resource utilization for the management of uncomplicated community-acquired pneumonia across community and children's hospitals. J Pediatr. 2014;165:585–91.
PubMedCentral CrossRef PubMed

Li P, To T, Parkin PC, Anderson GM, Guttmann A. Association between evidence-based standardized protocols in emergency departments with childhood asthma outcomes: a Canadian population-based study. Arch Pediatr Adolesc Med. 2012;166:834–40.
PubMed

Lougheed MD, Garvey N, Chapman KR, et al. Variations and gaps in management of acute asthma in Ontario emergency departments. Chest. 2009;135:724–36.
CrossRef PubMed

Mahant S, Pastor AC, Deoliveira L, Nicholas DB, Langer JC. Well-being of children with neurologic impairment after fundoplication and gastrojejunostomy tube feeding. Pediatrics. 2011;128:e395–403.
CrossRef PubMed

Manitoba Centre for Health Policy. http://umanitoba.ca/faculties/health_sciences/medicine/units/community_health_sciences/departmental_units/mchp/. Accessed 1 Mar 2015.

Martinez-Castaldi C, Silverstein M, Bauchner H. Child versus adult research: the gap in high-quality study design. Pediatrics. 2008;122:52–7.
CrossRef PubMed

McMorrow S. Will the Patient Protection and Affordable Care Act of 2010 improve health outcomes for individuals and families? Timely analysis of immediate health policy issues. Washington, DC: Urban Institute; 2010. http://www.urban.org/uploadedPDF/412127-2010-health-outcome.pdf

Melnyk BM, Grossman DC, Chou R, et al. USPSTF perspective on evidence-based preventive recommendations for children. Pediatrics. 2012;130:e399–407.
CrossRef PubMed

MHASEF Research Team. The mental health of children and youth in Ontario: a baseline scorecard. Toronto: Instittute for clinical Evaluative Sciences; 2015. http://www.ices.on.ca/Publications/Atlases-and-Reports/2015/Mental-Health-of-Children-and-Youth

Miglioretti DL, Johnson E, Williams A, et al. The use of computed tomography in pediatrics and the associated radiation exposure and estimated cancer risk. JAMA Pediatr. 2013;167:700–7.
PubMedCentral CrossRef PubMed

Moorman JE, Akinbami LJ, Bailey CM, et al. National surveillance of asthma: United States, 2001–2010. Vital Health Stat. 2012;35:1–67.

Morinis J, Maguire J, Khovratovich M, McCrindle BW, Parkin PC, Birken CS. Paediatric obesity research in early childhood and the primary care setting: the TARGet Kids! research network. Int J Environ Res Public Health. 2012;9:1343–54.
PubMedCentral CrossRef PubMed

Morse RB, Hall M, Fieldston ES, et al. Hospital-level compliance with asthma care quality measures at children's hospitals and subsequent asthma-related outcomes. JAMA. 2011;306:1454–60.
CrossRef PubMed

Moyer VA, Butler M. Gaps in the evidence for well-child care: a challenge to our profession. Pediatrics. 2004;114:1511–21.
CrossRef PubMed

Nakamura MM, Toomey SL, Zaslavsky AM, et al. Measuring pediatric hospital readmission rates to drive quality improvement. Acad Pediatr. 2014;14:S39–46.
CrossRef PubMed

National Committee for Quality Assurance. HEDIS measures. 2015. http://www.ncqa.org/HEDISQualityMeasurement/HEDISMeasures.aspx. Accessed 1 Mar 2015.

National Health Service. NHS atlas of variation in healthcare for children and young people. UK: National Health Service; 2012. http://www.rightcare.nhs.uk/index.php/atlas/children-and-young-adults/

National Health Service. The NHS atlas of variation in healthcare. UK: National Health Service; 2011. http://www.rightcare.nhs.uk/index.php/atlas/atlas-of-variation-2011/

National Paediatric Diabetes Audit, Royal College of Paediatrics and Child Health. National Paediatric Diabetes Audit Report 2013–2014. London: Royal College of Paediatrics and Child Health;

2015. http://www.rcpch.ac.uk/improving-child-health/quality-improvement-and-clinical-audit/national-paediatric-diabetes-audit-n-0

O'Connor AM, Bennett CL, Stacey D, et al. Decision aids for people facing health treatment or screening decisions. Cochrane Database Syst Rev . 2009;CD001431.

O'Leary M, Krailo M, Anderson JR, Reaman GH. Progress in childhood cancer: 50 years of research collaboration, a report from the Children's Oncology Group. Semin Oncol. 2008;35:484–93.
PubMedCentral CrossRef PubMed

Parikh K, Hall M, Mittal V, et al. Establishing benchmarks for the hospitalized care of children with asthma, bronchiolitis, and pneumonia. Pediatrics. 2014;134:555–62.
CrossRef PubMed

Patient Protection and Affordable Care Act, 42 U.S.C. § 18001 et seq. (2010).

Population Data BC. http://www.popdata.bc.ca/. Accessed 1 Mar 2015.

Shah PS, Lee SK, Lui K, et al. The International Network for Evaluating Outcomes of very low birth weight, very preterm neonates (iNeo): a protocol for collaborative comparisons of international health services for quality improvement in neonatal care. BMC Pediatr. 2014;14:110.
PubMedCentral CrossRef PubMed

Shipman SA, Lan J, Chang CH, Goodman DC. Geographic maldistribution of primary care for children. Pediatrics. 2011;127:19–27.
PubMedCentral CrossRef PubMed

Srivastava R, Landrigan CP. Development of the pediatric research in inpatient settings (PRIS) network: lessons learned. J Hosp Med. 2012;7:661–4.
CrossRef PubMed

The Dartmouth atlas of health care. http://www.dartmouthatlas.org/. Accessed 1 Mar 2015.

The Farr Institute of Health Informatics Research. http://www.farrinstitute.org. Accessed 1 Mar 2015.

Tieder JS, McLeod L, Keren R, et al. Variation in resource use and readmission for diabetic ketoacidosis in children's hospitals. Pediatrics. 2013;132:229–36.
CrossRef PubMed

To T, Guttmann A, Dick P. Inpatient and day surgery use by children in Ontario: ICES research atlas. Toronto: Institute for Clinical Evaluative Sciences; 2001.

To T, Curtis JR, Daneman D. Diabetes in children. In: Hux JE, Booth GL, Slaughter PM, Laupacis A, editors. Diabetes in Ontario: an ICES practice atlas. Toronto: Institute for Clinical Evaluative Sciences; 2003. p. 12.219–29.

Venekamp RP, Sanders S, Glasziou PP, Del Mar CB, Rovers MM. Antibiotics for acute otitis media in children. Cochrane Database Syst Rev. 2013;1, CD000219.
PubMed

Wasserman RC, Slora EJ, Bocian AB, et al. Pediatric research in office settings (PROS): a national practice-based research network to improve children’s health care. Pediatrics. 1998;102:1350–7.
CrossRef PubMed

Wennberg J, Gittelsohn A. Small area variations in health care delivery. Science. 1973;182:1102–8.
CrossRef PubMed

Wennberg JE, Mulley Jr AG, Hanley D, et al. An assessment of prostatectomy for benign urinary tract obstruction. Geographic variations and the evaluation of medical care outcomes. JAMA. 1988;259:3027–30.
CrossRef PubMed

Zylke JW, Rivara FP, Bauchner H. Challenges to excellence in child health research: call for papers. JAMA. 2012;308:1040–1.
CrossRef PubMed