

# Care System Redesign for Preterm Children After Discharge From the NICU

Dennis Z. Kuo, MD, MHS,<sup>a</sup> Robert E. Lyle, MD,<sup>b,c</sup> Patrick H. Casey, MD,<sup>b,c</sup> Christopher J. Stille, MD, MPH<sup>d</sup>

Approximately 1 in 8 children in the United States are born preterm. Existing guidelines and research examine the cost of prematurity from the NICU stay and developmental surveillance and outcomes after discharge from the NICU. Preterm children are at greater risk for excess hospitalizations, outpatient visits, and societal costs after NICU discharge. Improved delivery of care and health promotion from the community setting, particularly from the patient-centered medical home, may result in improved growth, health, and development, with accompanying reduction of post-NICU discharge costs and encounters. There has been comparatively little focus on how to promote health and wellness for children born preterm, particularly for community-based providers and payers. Accordingly, health care delivery for NICU graduates is often fragmented, with little guidance on medical management beyond tertiary care follow-up. In this article, we use what is known about chronic care and practice transformation models to present a framework for health care system redesign for children born preterm. We discuss the rationale for NICU graduates as a priority population for health system redesign. Promotion of health and wellness for children born preterm who are discharged to the community setting entails population health management from the patient-centered medical home; comanagement, clinical care protocols, and clinical support from the tertiary care-based tertiary care-based center; and a favorable payer strategy that emphasizes support for chronic care management. Practical suggestions are provided for the practicing physician for the child born preterm as health care systems are redesigned.

Approximately 8% of births result in a stay in the NICU.<sup>1</sup> Many admissions to the NICU are caused by prematurity, defined by 37 weeks' gestation or earlier, which accounts for 1 in 8 (~450 000) children born in the United States each year.<sup>2</sup> Preterm infants are at increased long-term risk for poor growth, chronic respiratory disease, and neurodevelopmental disabilities, particularly if they are extremely preterm and/or have very low birth weight.<sup>3-7</sup> Many graduates of the NICU will require chronic care management

after discharge, with needed services including frequent primary care visits, multispecialty care, and community-based early intervention services.<sup>8,9</sup>

Health care reform initiatives are increasingly calling for targeted management and system redesign for patients at risk for excessive health care use, specifically hospitalizations and emergency department visits.<sup>10</sup> System redesign for patients in need of chronic care management typically entails developing population registries of patients at risk. Such

## abstract

<sup>a</sup>Department of Pediatrics, University at Buffalo, Buffalo, New York; <sup>b</sup>Department of Pediatrics, University of Arkansas for Medical Sciences, Little Rock, Arkansas; <sup>c</sup>Arkansas Children's Research Institute, Little Rock, Arkansas; and <sup>d</sup>Children's Hospital Colorado, Aurora, Colorado

Dr Kuo conceptualized and designed the study and drafted the initial manuscript; Drs Lyle and Casey analyzed and interpreted the study data and revised the manuscript for important intellectual content; Dr Stille designed the study, revised the manuscript for important intellectual content; and all authors approved the final manuscript as written.

**DOI:** 10.1542/peds.2016-2969

Accepted for publication Jan 12, 2017

Address correspondence to Dennis Kuo, MD, MHS, UBMD Pediatrics, Hodge Pediatrics, 125 Hodge Ave, Buffalo, NY 14222. E-mail: dkuo@upa.chob.edu

PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

Copyright © 2017 by the American Academy of Pediatrics

**FINANCIAL DISCLOSURE:** The authors have indicated they have no financial relationships relevant to this article to disclose.

**FUNDING:** This publication was made possible by grant R40MC23626 from the Health Resources and Services Administration, an operating division of the US Department of Health and Human Services. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Health Resources and Services Administration or the US Department of Health and Human Services.

**POTENTIAL CONFLICT OF INTEREST:** The authors have indicated they have no potential conflicts of interest to disclose.

**To cite:** Kuo DZ, Lyle RE, Casey PH, et al. Care System Redesign for Preterm Children After Discharge From the NICU. *Pediatrics*. 2017;139(4):e20162969

registries are then used to deliver intensive case management, create accountable care quality metrics, and develop integrated care delivery systems with comanagement between multiple providers.<sup>11</sup> All preterm children require close follow-up in the community-based primary care setting. Some preterm children have further medical complexity and a high level of family-identified needs, requiring extensive system-based changes incorporating inpatient, outpatient, and community-based service providers.<sup>12</sup>

In this article, we outline the reasons that children born preterm and discharged to home from the NICU setting should be considered a priority population for health care system redesign. Existing guidelines and manuscripts addressing postneonatal care have tended to focus on tertiary care-based medical management, emphasizing neonatology and specialty follow-up, with limited focus on clinical management in outpatient care settings, particularly primary care.<sup>13-16</sup> To our knowledge, no previous work provides a broader health systems perspective that integrates multiple facets of postneonatal care that are aligned with health care reform initiatives. Such a perspective can help inform policy decisions relevant to population health and payment initiatives relevant to accountable care.

### **PUBLIC HEALTH AND ECONOMIC IMPACT OF PRETERM INFANTS AFTER NICU DISCHARGE**

Prematurity is estimated by the Institute of Medicine to cost more than \$26 billion to the US health care system each year, with the majority of these costs being from the inpatient setting.<sup>17</sup> Approximately 6% of preterm children are born under 28 weeks and are thus at the highest risk for

medical complications. Much of this cost results from care provided in the NICU setting, but significant utilization and costs continue to be incurred after discharge. Children born prematurely typically remain in the NICU until they achieve physiologic stability, usually around a postgestational age of 36 to 37 weeks or 2000 g, along with adequate weight gain.<sup>14</sup> Preterm infants then require frequent outpatient visits and prescription medication use, with one study finding a rate of 20 outpatient visits in the first year, most of them in the primary care setting.<sup>8</sup> Common medical issues that may require additional specialty care include bronchopulmonary dysplasia, gastroesophageal reflux, retinopathy of prematurity, and neurodevelopmental problems.<sup>15</sup> Contemporary NICU care has resulted in more children discharged from the hospital with assistive devices such as gastrostomy tubes and tracheostomies. These myriad service needs may cause substantial stress for parents, particularly in the presence of chronic conditions and neurodevelopmental disabilities.<sup>18</sup> Children born prematurely are at risk for behavioral disorders such as attention-deficit hyperactivity disorder, autism spectrum disorder, and a range of behavioral disorders such as anxiety and mood disorders.<sup>19</sup> The effects of prematurity may persist well into adolescence and adulthood, with prematurity associated with adult hypertension, obesity, lipidemia, insulin resistance, and a range of psychiatric disorders.<sup>19-21</sup>

Little research exists on what costs and utilization may be preventable with optimal management of preterm infants after NICU discharge.<sup>22</sup> However, excess hospitalizations do occur compared with term children, particularly in

the first 2 years after discharge.<sup>23</sup> The rate of hospital readmission of preterm infants during the first year of life ranges from 15% to 23%,<sup>24,25</sup> with extremely low birth weight (ELBW) infants having readmission rates approaching 50%.<sup>26</sup> Pulmonary disease is the predominant cause for rehospitalization, with other causes including surgical, infectious, and growth and nutrition.<sup>27</sup> Male ELBW infants and those with prolonged NICU stay for pulmonary reasons, a history of necrotizing enterocolitis stage II, ventriculoperitoneal shunts, and/or a prolonged oxygen requirement need tend to be at the highest risk for readmission, with 66% of ELBW infants with hospital stays <120 days for pulmonary reasons being rehospitalized in the first year.<sup>27</sup> Late preterm infants, defined as 33 to 36 weeks' gestation, are hospitalized at a greater rate than term infants, driving overall costs that are 3 times as high as term infants after discharge.<sup>28</sup> The greater number of late preterm infants, as compared with those born under 33 weeks, results in the greatest overall cost burden to the health care system.<sup>29</sup> Additional societal costs of preterm infants include the cost of early intervention, special education, and lost employment.<sup>30</sup>

Given excess hospitalizations, outpatient visits, and short- and long-term societal costs after NICU discharge, it is plausible that growth, health, and development of preterm children in the short and long term may be enhanced by improved delivery of care. In addition, post-NICU discharge costs and encounters in the short term may be altered, and long-term trajectories of adult health may be affected. Optimal achievement of health and development for preterm children entails appropriate growth, timely management of acute and chronic conditions, prevention of medical

complications, timely developmental screening and intervention, proactive recognition and management of behavioral disorders, and support for families as needed. The need for care coordination, chronic care self-management, and community-based care suggests a broad systems approach, beginning with the primary care setting. We suggest the use of chronic care management and practice transformation frameworks to address the needs of NICU graduates.

Preterm newborns, like all children, should receive routine health supervision visits based in the primary care-based medical home.<sup>31</sup> These health supervision visits provide the first line of care that optimizes growth and development, yet preterm infants are at risk for not receiving all recommended preventive care.<sup>32</sup> There is also little research on what constitutes effective delivery of preventive care of the NICU graduate from the primary care setting. Articles focusing on primary care management have largely been published before more recent advances in NICU care such as increased use of sildenafil for persistent pulmonary hypertension of the newborn. Guidelines generally focus on topics of clinical care management but typically do not discuss how to ensure effective delivery of recommended care and from which setting care may be delivered. Many primary care physicians report that their practices are not designed to optimally manage the spectrum of care needs of children with medical complexity. Reasons for discomfort include lack of time, lack of clinical expertise and comfort with the care of the child born prematurely, inadequate payments, insufficient personnel training in meeting family psychosocial needs, and a lack of communication skills across care settings.<sup>33–36</sup>

### **CHRONIC CARE AND PRACTICE TRANSFORMATION FRAMEWORKS GUIDE HEALTH CARE SYSTEM REDESIGN BASED IN THE PRIMARY CARE-BASED MEDICAL HOME**

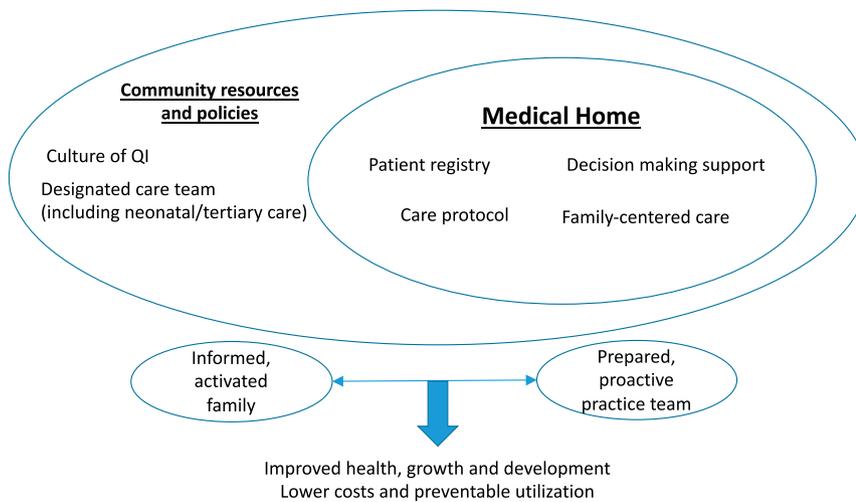
Health care system redesign for NICU graduates is based on a population health approach. Such an approach designates NICU graduates as a priority population and develops interdisciplinary teams based on the entirety of prematurity instead of individual encounters and problems.<sup>37</sup> Chronic care management frameworks, such as the Chronic Care Model,<sup>38</sup> define the components of effective care delivery for children with chronic care needs; these components also apply to NICU graduates. The primary care physician may oversee much of this care as the director of the medical home of the child.<sup>31</sup> Components of chronic care delivery may include decision support and clinical expertise, linkages with community resources, self-management support for patients and families, and medical practice transformation that use clinical information systems.<sup>39</sup> For the NICU graduate, decision-making support such as care protocols and bidirectional communication with a consulting tertiary care-based center may be necessary to support effective management from the primary care setting.

Effective management of NICU graduates may also entail practice transformation, which supports systematic changes in organization and processes within the primary care practice to support population health management.<sup>40</sup> Four essential drivers for practice transformation include (1) a culture of quality improvement (QI); (2) delivery of family-centered care, with parents as partners in the QI process; (3) team-based care; and (4) provision of care coordination.<sup>41</sup> Care coordination emphasizes reciprocal and bidirectional communication among all providers and families,

and care coordination and planning should address the patient's and family's need for services, support, and information.<sup>42</sup> Streamlining services and minimizing the direct care burden through direct family support and system-level approaches may reduce caregiver stress, improve family well-being, and enhance collaboration between families and providers.<sup>43</sup> However, provision of care coordination and transformation of a practice can also entail significant disruption to practice organization and care delivery. Practices require engaged, visible leadership and an explicit strategy for process improvement when improving care of the NICU graduate.<sup>44</sup>

Figure 1 shows the proposed framework for caring for the NICU graduate that are aligned with the Chronic Care Model and practice transformation. Highlights include the following:

- Culture of quality improvement. Leadership may publicly emphasize the importance of appropriate care of the NICU graduate and stepwise improvements in care delivery informed by data. Patient registry, workflow process mapping, care protocols, and use of data for process and outcomes improvement should be emphasized.
- Patient registry. Preterm infants should be identified and tracked from NICU discharge by the primary care practice. The resulting patient registry can be used for QI purposes, including creation of patient data to measure outcomes and inform changes, and acuity scoring, identifying patients with greater need for intensive case management based on medical or social complexity.
- Clinical care protocol. Care may be standardized among providers to take advantage of decision-making



**FIGURE 1** Conceptual framework of effective care delivery for preterm infants in the primary care setting based on Chronic Care Model and Practice Transformation model of care.

support. The protocol should be evidence- or guideline-based when available, with outcomes used for QI data purposes.

- Designated care team. Each preterm infant should have a designated physician who provides continuity of care, and a practice staff member such as a nurse who acts as a key contact and/or provides care coordination.
- Decision-making support. Each care team should have appropriate access to a consulting neonatologist and/or tertiary care service such as a high-risk follow-up program who may provide expertise and guidance as needed, particularly for aspects of clinical management such as oxygen support, feeding management, and developmental surveillance.
- Family-centered care. Practitioners should be versed in the principles of partnership and the culture of family-centered care, including shared-decision making, self-management, and utilizing families as partners in the QI team process.<sup>45</sup>

### CLINICAL DECISION-MAKING AND PRACTICE SUPPORT

While Bright Futures is the standard of preventive care for all children,<sup>46</sup> there are no consensus-based clinical care guidelines for primary care specific to preterm infants. Care protocols and decision support tools may be developed within practices using available evidence or guidelines. The initial visit should occur as soon as possible after discharge, preferably within 72 hours. Monthly, or even more frequent, visits may initially be appropriate to establish continuity of care, relationship building, and chronic care management from the primary care setting while assisting the family with all health and emotional concerns as the transition from NICU to home is completed

Clinical judgment to maintain adequate weight gain and health remains the standard in many situations. For this reason, care is best delivered with close working relationships between primary and tertiary care. The primary care physician can oversee the overall care management, such as ensuring adequate growth at 20 to 25 g per day after discharge as the goal, with tracking of weight, length, head

circumference, and weight/length ratio to ensure a gradual return to normal growth velocity.<sup>47</sup> All children should be offered breast milk when possible, supplemented with postdischarge preterm formula if needed, or provided transitional preterm formulas until up to 12 months chronologic age.<sup>48</sup> Multivitamin with iron should be considered for all preterm infants, particularly for breastfed infants or preterm infants at risk for anemia. Feeding aversion and reflux are common and should be diagnosed with a high index of suspicion and managed accordingly. If the child is on supplemental oxygen, weaning should be done in consultation with a neonatologist or pulmonologist. Indications for monthly screening laboratories include anemia at discharge, poor growth, or diuretic therapy.

Many graduates of the NICU will have referrals made to specialists upon discharge. Common subspecialty involvement may include ophthalmology for follow-up of retinopathy of prematurity<sup>49</sup>; pulmonary or neonatology for chronic lung disease and oxygen use; gastroenterology for feeding difficulties; and developmental pediatrics, neurology, and/or neurosurgery for neurologic conditions. Some graduates of the NICU may be referred to high-risk newborn follow-up services for medical management and developmental follow-up. Most such services typically do not provide round-the-clock care or preventive care consistent with the medical home model and in those cases should be used as a consultative service to the primary care setting. Routine developmental assessments should be performed for very low and low birth weight infants<sup>50</sup> and appropriate referrals made and verified. Comanagement with a lead primary care physician with a common care plan and bidirectional

communication with specialty colleagues should be the standard,<sup>51</sup> unless otherwise agreed on with the close involvement of a high-risk newborn follow-up service.

### **SYSTEM TRANSFORMATION AND ALIGNMENT WITH HEALTH CARE REFORM**

The health care reform environment may be increasingly conducive to system transformation that encourages additional management of preterm infants from the primary care setting. The Affordable Care Act of 2009 proposed support for testing innovative models of care that target high resource utilizers in the primary care setting.<sup>10</sup> The US Department of Health and Human Services is focusing interventions on patients with multiple chronic conditions, emphasizing health system changes, self-management, clinical practice guidelines, and research in this population.<sup>52</sup> Payment reforms, clinical practice guidelines, and outcomes research have the potential to transform the care of the preterm infant after NICU discharge.

Clinical leaders may choose to focus on the care of preterm infants within the practice setting for reasons including population health management and quality improvement. Population management of preterm infants requires a registry that has prospectively identified eligible infants for tracking, monitoring, and dedicated resources if warranted. Existing algorithms to identify children at high risk depend on the existence of claims histories that are used to develop risk strata.<sup>53-55</sup> Claims histories from the previous year do not exist for the child <1 year of age. Instead of being automatically identified and entered, children who are born preterm may need to be entered manually into a population registry at the practice level. An alternative is to implement

statewide tracking of preterm infants upon discharge from the NICU. Consideration should be made to identify different risk strata within preterm infants, such as weight, gestational age, and additional medical or social complications.<sup>56</sup>

New payment models may enable primary care practices to earn prospective payments for chronic care management and practice management.<sup>10</sup> With prospective care coordination payments, resources may be allocated to develop the care teams with a designated member to act as a care coordinator, track data, provide direct patient education, develop and maintain a care plan with the family, and screen for family well-being and stressors while addressing caregiver support needs. Such staffing and education may extend to other children with chronic health conditions. Electronic health care plans that can be updated regularly may be implemented in coordination with family input.

Accountable care organizations may play an increasing role in care delivery and financing. Care delivery models may include care coordination, case management, and home visiting services that address social determinants of health and complement the medical management of the primary care service. Children born prematurely and discharged from the NICU may be inherently difficult to assign to a delivery risk stratum due to their lack of long-term claims history and the fact that much of their initial cost is incurred in the hospital setting. Nonetheless, the potential for cost reduction is significant with the relatively high hospitalization rates for certain children and the complexity of health care services that many preterm infants require. Quality measures may include preventive, acute, and chronic care, addressing physical assessment, nutrition, communication between providers, developmental screening,

and psychosocial evaluations.<sup>50</sup> A financial incentive for shared savings for practices, if available, would come from reduction of preventable emergency department or inpatient admissions.

### **FUTURE QUESTIONS FOR RESEARCH**

Federal health care priorities, chronic care models, and payment reforms are increasingly supportive of chronic care management in the primary care setting. The epidemiology, high health care service need and cost, and potentially preventable encounters characteristic of many children born prematurely make this group of patients an important target for population research. Additional research must be done to help support comprehensive management of such children through the primary care setting.

Consensus and evidence-based primary care management guidelines will be helpful for clinicians, administrators, and policymakers alike. Although individual needs of NICU graduates vary considerably, all need a certain level of population management with a common set of care goals. Sample research questions and clarification include the length of time to feed preterm formula, which children might benefit from automatic developmental evaluation and enrollment in Early Intervention programs, and the appropriate visit frequency to primary care settings in addition to existing Bright Futures guidelines. The optimal growth pattern should strike a balance between sufficient nutrition to promote lung and brain development and excess feeding that might put a child at risk for obesity and cardiovascular disease. Consensus guidelines would facilitate further development of quality measures for accountable care organizations and encourage practices to adhere to a set pattern of care delivery.

The mechanisms for improved care and clinical outcomes should be better elucidated. Aspects of care that lack consistent guidelines include visit frequency, duration of premature formula, monitoring laboratories such as hemoglobin and alkaline phosphatase, hearing screening, oxygen weaning, and developmental screening referral or frequency. Desired clinical outcomes include appropriate weight gain, timely development, reduced family stress, and avoidance of emergency department and hospital use. It is currently unclear what type of care interventions, such as provider education, community linkages, a dedicated care coordinator, round-the-clock access to a knowledge clinical service, or a supportive consulting tertiary care center service will reliably result in optimal outcomes.<sup>57,58</sup> The ideal frequency of primary care visits and type of visits, as well as what is managed in such visits, is also unknown, along with important staff roles. Some potentially avoidable health care encounters may be mitigated by improved growth and nutrition, others by improved self-management taught at preventive care visits, and still others by intensive management by a care coordinator or home visitor based out of a primary care practice, a tertiary care center, an accountable care organization, or other model. With limited resources, choices will be made as to which interventions to support.

Finally, the potential for savings through improved chronic care management for this population is not well defined. The threshold for hospital admission is likely understandably lower for children born prematurely, so it is unclear what types of admissions may be avoidable with better home care, nutrition, or timely intervention. These figures are important to understand for accountable care organizations seeking a return on

investment. More difficult to answer is the lifetime return on investment made by improved care in the postneonatal period for children at risk.<sup>59</sup>

## CONCLUSIONS

Children who are born prematurely continue to incur high resource use and costs in the first 2 years after discharge from the NICU. These characteristics make such children an appropriate group for population health management and system redesign. Improvements in health and development, and reduction in costs, may occur with chronic care management and practice transformation in the primary care setting. Population management, registry enrollment, tracking, and care coordination in the primary care outpatient setting should be offered to all children born prematurely and graduate from the NICU, but particularly those at highest risk for hospitalization. Future research should address the potential for savings and return on investment in the outpatient setting, clinical tracking measures, and appropriate clinical consensus guidelines for care in the primary care setting.

## ABBREVIATIONS

ELBW: extremely low birth weight

QI: quality improvement

## REFERENCES

1. Harrison W, Goodman D. Epidemiologic trends in neonatal intensive care, 2007–2012. *JAMA Pediatr.* 2015;169(9):855–862
2. Martin JA, Hamilton BE, Osterman MJK, Curtin SC, Mathews TJ. *Births: Final Data for 2012*. Hyattsville, MD: National Center for Health Statistics; 2013
3. Jarjour IT. Neurodevelopmental outcome after extreme prematurity: a

review of the literature. *Pediatr Neurol.* 2015;52(2):143–152

4. Serenius F, Källén K, Blennow M, et al; EXPRESS Group. Neurodevelopmental outcome in extremely preterm infants at 2.5 years after active perinatal care in Sweden. *JAMA.* 2013;309(17):1810–1820
5. McCormick MC, Litt JS, Smith VC, Zupancic JA. Prematurity: an overview and public health implications. *Annu Rev Public Health.* 2011;32:367–379
6. Msall ME, Tremont MR. Measuring functional outcomes after prematurity: developmental impact of very low birth weight and extremely low birth weight status on childhood disability. *Ment Retard Dev Disabil Res Rev.* 2002;8(4):258–272
7. Hack M, Taylor HG, Drotar D, et al. Chronic conditions, functional limitations, and special health care needs of school-aged children born with extremely low-birth-weight in the 1990s. *JAMA.* 2005;294(3):318–325
8. Wade KC, Lorch SA, Bakewell-Sachs S, Medoff-Cooper B, Silber JH, Escobar GJ. Pediatric care for preterm infants after NICU discharge: high number of office visits and prescription medications. *J Perinatol.* 2008;28(10):696–701
9. Saigal S, Doyle LW. An overview of mortality and sequelae of preterm birth from infancy to adulthood. *Lancet.* 2008;371(9608):261–269
10. Edwards ST, Abrams MK, Baron RJ, et al. Structuring payment to medical homes after the affordable care act. *J Gen Intern Med.* 2014;29(10):1410–1413
11. O'Donnell R. Reforming Medicaid for medically complex children. *Pediatrics.* 2013;131(suppl 2):S160–S162
12. Cohen E, Kuo DZ, Agrawal R, et al. Children with medical complexity: an emerging population for clinical and research initiatives. *Pediatrics.* 2011;127(3):529–538
13. Verma RP, Sridhar S, Spitzer AR. Continuing care of NICU graduates. *Clin Pediatr (Phila).* 2003;42(4):299–315
14. American Academy of Pediatrics Committee on Fetus and Newborn. Hospital discharge of the high-risk neonate. *Pediatrics.* 2008;122(5):1119–1126

15. McCourt MF, Griffin CM. Comprehensive primary care follow-up for premature infants. *J Pediatr Health Care*. 2000;14(6):270–279
16. Berger SP, Holt-Turner I, Cupoli JM, Mass M, Hageman JR. Caring for the graduate from the neonatal intensive care unit. At home, in the office, and in the community. *Pediatr Clin North Am*. 1998;45(3):701–712
17. Institute of Medicine (US) Committee on Understanding Premature Birth and Assuring Healthy Outcomes; Behrman RE, Butler AS, eds. *Preterm Birth: Causes, Consequences, and Prevention*. Washington, DC: National Academies Press; 2007
18. Drotar D, Hack M, Taylor G, Schluchter M, Andreias L, Klein N. The impact of extremely low birth weight on the families of school-aged children. *Pediatrics*. 2006;117(6):2006–2013
19. Montagna A, Nosarti C. Socio-emotional development following very preterm birth: pathways to psychopathology. *Front Psychol*. 2016;7:80
20. Lane RH. Fetal programming, epigenetics, and adult onset disease. *Clin Perinatol*. 2014;41(4):815–831
21. Singh GK, Kenney MK, Ghandour RM, Kogan MD, Lu MC. Mental health outcomes in US children and adolescents born prematurely or with low birthweight. *Depress Res Treat*. 2013;2013:570743
22. Petrou S, Davidson LL. Economic issues in the follow-up of neonates. *Semin Neonatol*. 2000;5(2):159–169
23. Johnston KM, Gooch K, Korol E, et al. The economic burden of prematurity in Canada. *BMC Pediatr*. 2014;14:93
24. Underwood MA, Danielsen B, Gilbert WM. Cost, causes and rates of rehospitalization of preterm infants. *J Perinatol*. 2007;27(10):614–619
25. Smith VC, Zupancic JA, McCormick MC, et al. Rehospitalization in the first year of life among infants with bronchopulmonary dysplasia. *J Pediatr*. 2004;144(6):799–803
26. Lamarche-Vadel A, Blondel B, Truffer P, et al; EPIPAGE Study Group. Re-hospitalization in infants younger than 29 weeks' gestation in the EPIPAGE cohort. *Acta Paediatr*. 2004;93(10):1340–1345
27. Ambalavanan N, Carlo WA, McDonald SA, Yao Q, Das A, Higgins RD; Generic Database and Follow-up Subcommittees of the Eunice Kennedy Shriver National Institute of Child Health and Human Development Neonatal Research Network. Identification of extremely premature infants at high risk of rehospitalization. *Pediatrics*. 2011;128(5). Available at: [www.pediatrics.org/cgi/content/full/128/5/e1216](http://www.pediatrics.org/cgi/content/full/128/5/e1216)
28. McLaurin KK, Hall CB, Jackson EA, Owens OV, Mahadevia PJ. Persistence of morbidity and cost differences between late-preterm and term infants during the first year of life. *Pediatrics*. 2009;123(2):653–659
29. Russell RB, Green NS, Steiner CA, et al. Cost of hospitalization for preterm and low birth weight infants in the United States. *Pediatrics*. 2007;120(1). Available at: [www.pediatrics.org/cgi/content/full/120/1/e1](http://www.pediatrics.org/cgi/content/full/120/1/e1)
30. Petrou S, Johnson S, Wolke D, Hollis C, Kochhar P, Marlow N. Economic costs and preference-based health-related quality of life outcomes associated with childhood psychiatric disorders. *Br J Psychiatry*. 2010;197(5):395–404
31. Medical Home Initiatives for Children With Special Needs Project Advisory Committee. American Academy of Pediatrics. The medical home. *Pediatrics*. 2002;110(1 pt 1):184–186
32. D'Agostino JA, Passarella M, Saynisch P, Martin AE, Macheras M, Lorch SA. Preterm Infant Attendance at Health Supervision Visits. *Pediatrics*. 2015;136(4). Available at: [www.pediatrics.org/cgi/content/full/136/4/e794](http://www.pediatrics.org/cgi/content/full/136/4/e794)
33. Van Cleave J, Okumura MJ, Swigonski N, O'Connor KG, Mann M, Lail JL. Medical homes for children with special health care needs: primary care or subspecialty service? *Acad Pediatr*. 2016;16(4):366–372
34. Kuo DZ, Robbins JM, Burns KH, Casey PH. Individual and practice characteristics associated with physician provision of recommended care for children with special health care needs. *Clin Pediatr (Phila)*. 2011;50(8):704–711
35. Agrawal R, Shah P, Zebracki K, Sanabria K, Kohrman C, Kohrman AF. Barriers to care for children and youth with special health care needs: perceptions of Illinois pediatricians. *Clin Pediatr (Phila)*. 2012;51(1):39–45
36. Tschudy MM, Raphael JL, Nehal US, O'Connor KG, Kowalkowski M, Stille CJ. Barriers to care coordination and medical home implementation. *Pediatrics*. 2016;138(3):e20153458
37. Nash DB. *The Population Health Mandate: A Broader Approach to Care Delivery*. San Diego, CA: The Governance Institute; 2012
38. Bodenheimer T, Wagner EH, Grumbach K. Improving primary care for patients with chronic illness: the chronic care model, part 2. *JAMA*. 2002;288(15):1909–1914
39. Bodenheimer T, Wagner EH, Grumbach K. Improving primary care for patients with chronic illness. *JAMA*. 2002;288(14):1775–1779
40. Sugarman JR, Phillips KE, Wagner EH, Coleman K, Abrams MK. The safety net medical home initiative: transforming care for vulnerable populations. *Med Care*. 2014;52(11 suppl 4):S1–S10
41. McAllister JW, Cooley WC, Van Cleave J, Boudreau AA, Kuhlthau K. Medical home transformation in pediatric primary care—what drives change? *Ann Fam Med*. 2013;11(suppl 1):S90–S98
42. Council on Children with Disabilities and Medical Home Implementation Project Advisory Committee. Patient- and family-centered care coordination: a framework for integrating care for children and youth across multiple systems. *Pediatrics*. 2014;133(5). Available at: [www.pediatrics.org/cgi/content/full/133/5/e1451](http://www.pediatrics.org/cgi/content/full/133/5/e1451)
43. Edelstein H, Schippke J, Sheffe S, Kingsnorth S. Children with medical complexity: a scoping review of interventions to support caregiver stress [published online ahead of print November 29, 2016]. *Child Care Health Dev*. 10.1111/cch.12430
44. Wagner EH, Gupta R, Coleman K. Practice transformation in the safety net medical home initiative: a qualitative look. *Med Care*. 2014;52(11 suppl 4):S18–S22
45. Kuo DZ, Houtrow AJ, Arango P, Kuhlthau KA, Simmons JM, Neff

- JM. Family-centered care: current applications and future directions in pediatric health care. *Matern Child Health J.* 2012;16(2):297–305
46. Hagan JF, Shaw JS, Duncan P, eds. *Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents.* 3rd ed. Elk Grove Village, IL: American Academy of Pediatrics; 2008
  47. Casey PH. Growth of low birth weight preterm children. *Semin Perinatol.* 2008;32(1):20–27
  48. Carver JD, Wu PY, Hall RT, et al. Growth of preterm infants fed nutrient-enriched or term formula after hospital discharge. *Pediatrics.* 2001;107(4):683–689
  49. Fierston WM; American Academy of Pediatrics Section on Ophthalmology; American Academy of Ophthalmology; American Association for Pediatric Ophthalmology and Strabismus; American Association of Certified Orthoptists. Screening examination of premature infants for retinopathy of prematurity. *Pediatrics.* 2013;131(1):189–195
  50. Wang CJ, McGlynn EA, Brook RH, et al. Quality-of-care indicators for the neurodevelopmental follow-up of very low birth weight children: results of an expert panel process. *Pediatrics.* 2006;117(6):2080–2092
  51. Stille CJ. Communication, comanagement, and collaborative care for children and youth with special healthcare needs. *Pediatr Ann.* 2009;38(9):498–504
  52. Parekh AK, Kronick R, Tavenner M. Optimizing health for persons with multiple chronic conditions. *JAMA.* 2014;312(12):1199–1200
  53. Neff JM, Sharp VL, Muldoon J, Graham J, Popalisky J, Gay JC. Identifying and classifying children with chronic conditions using administrative data with the clinical risk group classification system. *Ambul Pediatr.* 2002;2(1):71–79
  54. Starfield B, Weiner J, Mumford L, Steinwachs D. Ambulatory care groups: a categorization of diagnoses for research and management. *Health Serv Res.* 1991;26(1):53–74
  55. Simon TD, Cawthon ML, Stanford S, et al; Center of Excellence on Quality of Care Measures for Children with Complex Needs (COE4CCN) Medical Complexity Working Group. Pediatric medical complexity algorithm: a new method to stratify children by medical complexity. *Pediatrics.* 2014;133(6). Available at: [www.pediatrics.org/cgi/content/full/133/6/e1647](http://www.pediatrics.org/cgi/content/full/133/6/e1647)
  56. Doyle LW, Anderson PJ, Battin M, et al. Long term follow up of high risk children: who, why and how? *BMC Pediatr.* 2014;14:279
  57. Berry JG, Hall M, Neff J, et al. Children with medical complexity and Medicaid: spending and cost savings. *Health Aff (Millwood).* 2014;33(12):2199–2206
  58. Broyles RS, Tyson JE, Heyne ET, et al. Comprehensive follow-up care and life-threatening illnesses among high-risk infants: a randomized controlled trial. *JAMA.* 2000;284(16):2070–2076
  59. Stille C, Turchi RM, Antonelli R, et al; Academic Pediatric Association Task Force on Family-Centered Medical Home. The family-centered medical home: specific considerations for child health research and policy. *Acad Pediatr.* 2010;10(4):211–217

## Care System Redesign for Preterm Children After Discharge From the NICU

Dennis Z. Kuo, Robert E. Lyle, Patrick H. Casey and Christopher J. Stille

*Pediatrics* 2017;139;

DOI: 10.1542/peds.2016-2969 originally published online March 1, 2017;

### Updated Information & Services

including high resolution figures, can be found at:  
<http://pediatrics.aappublications.org/content/139/4/e20162969>

### References

This article cites 55 articles, 17 of which you can access for free at:  
<http://pediatrics.aappublications.org/content/139/4/e20162969#BIBL>

### Subspecialty Collections

This article, along with others on similar topics, appears in the following collection(s):  
**Community Pediatrics**  
[http://www.aappublications.org/cgi/collection/community\\_pediatrics\\_sub](http://www.aappublications.org/cgi/collection/community_pediatrics_sub)  
**Medical Home**  
[http://www.aappublications.org/cgi/collection/medical\\_home\\_sub](http://www.aappublications.org/cgi/collection/medical_home_sub)  
**Administration/Practice Management**  
[http://www.aappublications.org/cgi/collection/administration:practice\\_management\\_sub](http://www.aappublications.org/cgi/collection/administration:practice_management_sub)  
**System-Based Practice**  
[http://www.aappublications.org/cgi/collection/system-based\\_practice\\_sub](http://www.aappublications.org/cgi/collection/system-based_practice_sub)

### Permissions & Licensing

Information about reproducing this article in parts (figures, tables) or in its entirety can be found online at:  
<http://www.aappublications.org/site/misc/Permissions.xhtml>

### Reprints

Information about ordering reprints can be found online:  
<http://www.aappublications.org/site/misc/reprints.xhtml>

# American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN®



# PEDIATRICS®

OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

## Care System Redesign for Preterm Children After Discharge From the NICU

Dennis Z. Kuo, Robert E. Lyle, Patrick H. Casey and Christopher J. Stille  
*Pediatrics* 2017;139;

DOI: 10.1542/peds.2016-2969 originally published online March 1, 2017;

The online version of this article, along with updated information and services, is  
located on the World Wide Web at:

<http://pediatrics.aappublications.org/content/139/4/e20162969>

Pediatrics is the official journal of the American Academy of Pediatrics. A monthly publication, it has been published continuously since 1948. Pediatrics is owned, published, and trademarked by the American Academy of Pediatrics, 345 Park Avenue, Itasca, Illinois, 60143. Copyright © 2017 by the American Academy of Pediatrics. All rights reserved. Print ISSN: 1073-0397.

## American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN®

