

# Transforming Children's Health Care Quality and Outcomes—A Not-So-Random Non-linear Walk Across the Translational Continuum

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WE WERE DELIGHTED to see passage of the Children's Health Insurance Program Reauthorization Act of 2009 (CHIPRA).<sup>1</sup> CHIPRA provides unprecedented opportunities and resources for the US Department of Health and Human Services and its components to work with a broad range of stakeholders to improve the quality of health care delivered to the nation's children. The initial focus is on the almost 40 million children enrolled in Medicaid and CHIP, and the goal is better care for all children.

In this commentary, we use concepts of the translational continuum from basic biomedical research to optimal population health (Figure).<sup>2–8</sup> We note the contributions that CHIPRA makes to overcoming what we have characterized as the third translational block—between sufficient knowledge of clinical effectiveness and reliable delivery of safe and effective services at every patient's bedside—and suggest that for substantial improvements to be made in children's health care and health, additional attention must be paid to all components of the translational continuum.

## THE TRANSLATIONAL CONTINUUM

As shown in the Figure, basic biomedical knowledge is considered the foundation of health care delivery and optimal child health. As an example of the priority put on basic bioscience, there is much work underway to understand human genetics, believed to be the most critical building blocks of human health.<sup>9</sup> However, as is now familiar to the clinical research and health care delivery communities, basic knowledge about mechanisms of action in the human body and brain does not by itself improve health. That basic information must be used to develop efficacious and effective clinical and public health interventions (eg, drugs, devices, and patient behavior change interventions). It is now well accepted that numerous factors inhibit the translation of knowledge from basic biomedical research into clinical efficacy trials, and from clinical efficacy trial findings to clinical effectiveness research and results. These factors continue to be characterized

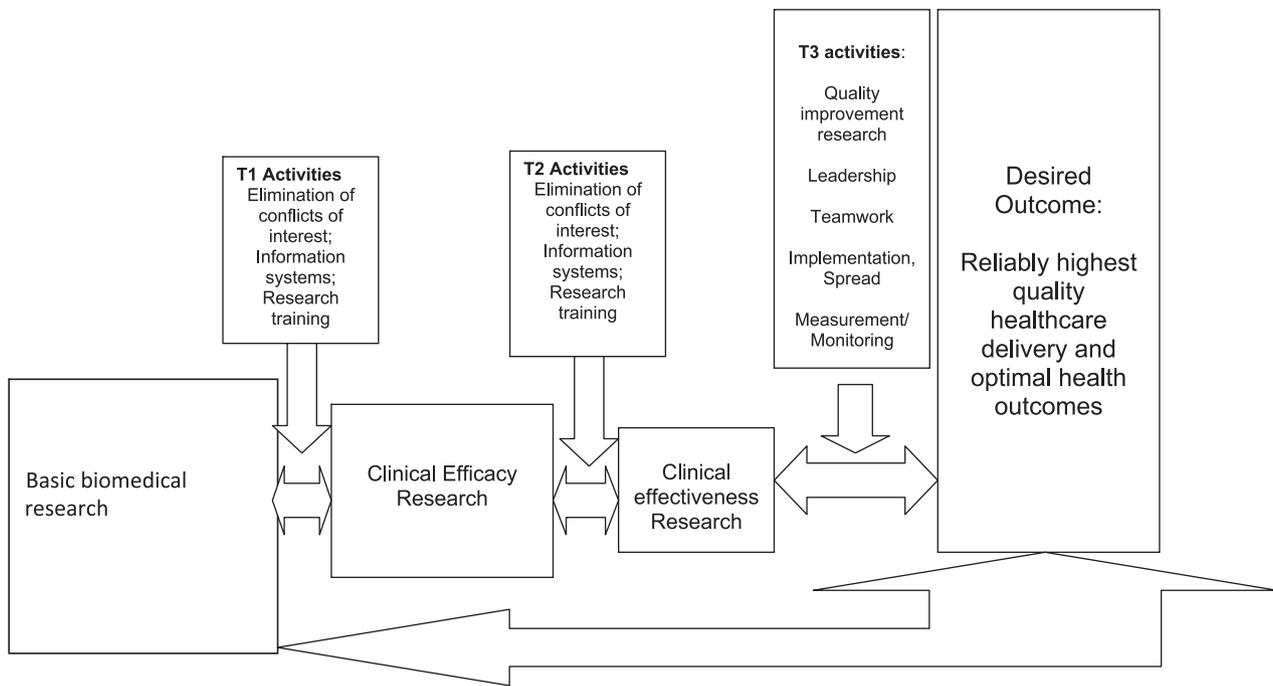
and are commonly grouped into so-called “translational blocks” 1 and 2.<sup>4,5</sup>

Despite work under way to overcome translational challenges in blocks 1 and 2, greater attention to clinical efficacy and effectiveness research will not be enough to get effective care reliably to all Americans at points of care.<sup>10,11</sup> We have characterized this new set of challenges by using the term *the third translational block* and suggested approaches to overcoming this third set of challenges.<sup>3</sup> These approaches include increased support for a different kind of research and evaluation (ie, understanding and testing health care quality improvement<sup>12</sup>), as well as nonresearch endeavors, including enhanced leadership and teamwork for health care quality improvement, and greater attention to monitoring health care quality and disparities in quality and taking strong action to reduce gaps.

In this commentary, we suggest that the quality portions of CHIPRA contribute greatly to overcoming the third translational block between clinical knowledge and improved care quality and outcomes, but that to make even more substantial improvements in children's health care and health, more attention to children's clinical research is needed. This additional attention may mean focusing additional resources on the more traditional first and second translational blocks.

## CHIPRA MAKES HEADWAY TOWARD OVERCOMING THE THIRD TRANSLATIONAL BLOCK

As noted above, crossing the third translational block requires leadership and teamwork, quality monitoring, and action to address gaps in quality, including disparities in care. Congress demonstrated leadership by writing and passing CHIPRA, which in turn supports additional leadership and teamwork across the US Department of Health and Human Services and State Medicaid and CHIP programs. The CHIPRA focus on measurement and related reporting<sup>1,13,14</sup> is essential for monitoring progress in



**Figure.** Transformation of health care delivery across the translational continuum: research and action. Adapted from Dougherty and Conway, 2008<sup>3</sup>; Murrillo et al, 2003<sup>2</sup>; Sung et al, 2003<sup>4</sup>; Szilagy, 2009.<sup>6</sup>

children's health care quality. CHIPRA also includes a major quality improvement initiative at the state level, which focuses on provider-based quality improvement interventions, testing a model electronic health record format and other health information technology implementation, and system-wide changes such as medical home interventions.<sup>14</sup> Findings from these improvement efforts will be summarized and shared widely.

#### NEED FOR MORE EVIDENCE OF CLINICAL EFFECTIVENESS OF SERVICES FOR CHILDREN

Despite the attention in CHIPRA to translation 3 activities, the evidence grading exercise used during identification of the initial recommended core set of children's health care quality measures provides compelling confirmation of the need for activities earlier in the translational continuum.<sup>15</sup> In the end, only 2 initial core CHIPRA measures were able to be given the highest evidence grade of A, using as a basis for grading the Oxford Centre for Evidence Based Medicine.<sup>16</sup> Thirteen measures in the core set received grades of B (including, but not limited to, prenatal care frequency and timing, low birthweight, low-risk C-section rates, immunizations, well-child care visits, developmental screening, chlamydia screening, pediatric central line associated blood stream infections). One measure received a grade of C (emergency department visits as an indication of poor quality asthma care), and several measures received D grades (dental treatment, attention-deficit/hyperactivity disorder follow-up, hemoglobin A<sub>1c</sub> testing for children with diabetes). Although evidence-grading schemes can be controversial, grades such as these are consistent with the experience of the US

Preventive Services Task Force<sup>17</sup> findings of Agency for Healthcare Research and Quality's (AHRQ) evidence-based practice center program<sup>18</sup> and similar entities and reviews.<sup>19,20</sup> In essence, it is rare to find grade A evidence in children's clinical literature, even for services that are provided every day to tens of millions of children. Although a lack of evidence does not necessarily mean that services are not effective, the paucity of high-grade evidence could cast doubt on the utility of the initial core set. Therefore, it is critical to take steps to add to the evidence base.

New efforts are under way that should help build the clinical evidence base in children's health. Optimally, the new pediatric focus in the National Institutes of Health-supported Clinical and Translational Science Awards will accelerate activities to cross the first translational block—from basic biomedical science findings to clinical efficacy research—and beyond.<sup>21</sup> Refreshed Better Pharmaceuticals for Children Act activities should also help transform basic science into child-safe and effective drug treatments. In federal fiscal years 2009 and 2010 (October 1, 2008 to September 30, 2010), 42 pediatric-relevant comparative effectiveness research projects were funded by AHRQ and National Institutes of Health using American Recovery and Revitalization Act funds, for a total of \$7.6 million.<sup>22</sup> Projects focus on a variety of topics (eg, attention-deficit hyperactivity disorder, HIV prevention, reproductive medicine, autism spectrum disorders, cleft lip and palate, and juvenile idiopathic arthritis). Patient-Centered Outcomes Research initiatives under the Patient Protection and Affordable Care Act of 2010 may help address the second translational block through even more focus on high-priority areas for comparative effectiveness research.<sup>23,24</sup>

A major step forward in evidence development and assessment in children's health care is the increasing consideration of methods and infrastructures other than the randomized controlled trial, given the challenges inherent in children's clinical research (eg, small numbers of children with specific conditions).<sup>25</sup> For example, registries are being created to track children identified through newborn screening.<sup>26</sup> Carefully done, such registries can identify patterns and details of care for children along with detailed child characteristics, to begin to assess which treatments may be most effective for which children. Randomized controlled trials can then be carefully designed to comparatively test the most promising treatments. AHRQ is funding several child-relevant health care quality improvement research projects to identify the "how" and "why" of effective implementation.<sup>27</sup>

Addressing whether existing resources will be enough to address the gaps in children's health care science that impede improving children's health outcomes is beyond the scope of this commentary. Given longstanding concerns about the resources available for pediatric research,<sup>28–30</sup> more in-depth analysis could be helpful and lead to a prioritized clinical research agenda in child health.<sup>6</sup> Setting research priorities can be a difficult topic given the variety of criteria, but several approaches are emerging and could be adapted for use within the translational continuum. For example, the AHRQ National Advisory Council on Healthcare Quality and Research Subcommittee on Children's Healthcare Quality Measures for Medicaid and CHIP (SNAC) agreed on criteria for the importance of child health topics for quality measurement, and the SNAC itself identified important areas for future measure development.<sup>14</sup> The article by Dougherty and colleagues<sup>31</sup> in this issue provides additional detail on prevalence and costs for selected conditions that may be useful in setting priorities. More high-priority areas are forthcoming from analysis of the request for public input posted in December 2010.<sup>32</sup>

## BEYOND A LINEAR APPROACH TO CROSSING THE QUALITY CHASM

It is important to note that although it is convenient to portray the translational continuum as a pyramid<sup>33</sup> or timeline (Figure), progress is never linear. The absence of knowledge of causation need not impede efforts to test promising clinical interventions and to apply knowledge broadly as soon as it is appropriate. For example, the causes of asthma, premature birth, low birthweight, childhood obesity, and adolescent depression are not yet fully known, but there is evidence of the effectiveness of some prevention and treatment approaches for these conditions. The need for better evidence should not slow down efforts to implement what is known to work now. More effort could also be put into developing and spreading effective health care quality improvement strategies to bring effective clinical interventions to more children.<sup>34</sup>

We believe that to motivate additional efforts to improve health care quality for children attention must be paid to

the following: 1) *simultaneously* overcoming the first and second translation blocks that hinder movement from basic biomedical discovery to clinical efficacy, and clinical efficacy to clinical effectiveness; and 2) *simultaneously* overcoming the third translational block between demonstrated effectiveness and reliable delivery to every child who can benefit from the intervention. In addition, as shown in the Figure, these activities should not be linear—we need continuous feedback and feed forward loops across the continuum. Without a solid clinical evidence base, providers, health plans, states, and families may be unlikely to take the trouble to engage in measurement and participate in quality improvement initiatives. Without focused attention to activities beyond basic and clinical research, the fruits of such research will wither, and children will never receive the high quality of care or health outcomes envisioned by those who drafted the CHIPRA legislation. Without continuous productive interactions back and forth across the continuum, our efforts will continue to be siloed and progress will be slow.

## REFERENCES

1. US Congress. Public Law 111-3, The Children's Health Insurance Program Reauthorization Act Feb. 4. Available at: [http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=111\\_cong\\_public\\_laws&docid=f:pub1003.111](http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=111_cong_public_laws&docid=f:pub1003.111). Accessed January 9, 2010.
2. Murrillo et al. 2003.
3. Dougherty D, Conway P. The "3Ts" roadmap to transform US health care: the 'how' of high-quality care. *JAMA*. 2008;299:2319–2321.
4. Sung N, Crowley WJ, Genel M, et al. Central challenges facing the national clinical research enterprise. *JAMA*. 2003;289:1278–1287.
5. Sussman S, Valente T, Rohrbach L, et al. Translation in the health professions: converting science into action. *Eval Health Prof*. 2006;29:7–32.
6. Szilagyi P. Translational research and pediatrics. *Acad Pediatr*. 2009;9:71–80.
7. Murillo H, Reece A, Synderman R, Sung N. Meeting the challenges facing clinical research: solutions proposed by leaders of medical specialty and clinical research societies. *Acad Med*. 2006;81:107–112.
8. Pronovost P, Cardo D, Goeschel C, et al. A research framework for reducing preventable patient harm. *Clin Infect Dis*. 2011;52:507–513.
9. Varmus H. Ten years on—the human genome and medicine. *NEJM*. 2010;362:2028–2029.
10. Agency for Healthcare Research and Quality. Measuring healthcare quality. Available at: <http://www.ahrq.gov/qual/measurix.htm>. Accessed August 27, 2010.
11. Bethell C, Kogan M, Strickland B, et al. A national and state profile of leading health problems and health care quality for US Children: key insurance disparities and across-state variations. *Acad Pediatr*. 2011;11(suppl 3):S22–S33.
12. Agency for Healthcare Research and Quality. *Researching Implementation and Change while Improving Quality (R18)*. Available at: <http://grants.nih.gov/grants/guide/pa-files/PAR-08-136.html>. Accessed May 15, 2008.
13. Agency for Healthcare Research and Quality. Improving the initial core set: the CHIPRA Pediatric Quality Measures Program. Available at: <http://www.ahrq.gov/chipra/#Core2>. Accessed March 7, 2011.
14. Mann C. A new era for state Medicaid and Children's Health Insurance Programs. *Acad Pediatr*. 2011;11(suppl 3):S95–S96.
15. Mangione-Smith R, Schiff J, Dougherty D. Identifying children's health care quality measures for Medicaid and CHIP: an evidence-informed, publicly transparent expert process. *Acad Pediatr*. 2011;11(suppl 3):S11–S22.

16. Oxford Centre for Evidence Based Medicine. Levels of Evidence. Glossary. Available at: <http://www.cebm.net/?o=1116>. Accessed January 12, 2011.
17. US Preventive Services Task Force. Child and adolescent recommendations. Available at: <http://www.uspreventiveservicestaskforce.org/ftchildcat.htm>. Accessed December 29, 2010.
18. Agency for Healthcare Research and Quality. Evidence-based practice. Available at: <http://www.ahrq.gov/clinic/epcix.htm>. Accessed December 29, 2010.
19. The Cochrane Child Health Field Web site. Available at: <http://www.cochranechildhealth.ualberta.ca/>. Accessed December 29, 2010.
20. Moyer V, Butler M. Gaps in the evidence for well-child care: a challenge to our profession. *Pediatrics*. 2004;114:1511–1521.
21. Heubi J. Child health research and the clinical translational science awards: where have we been and where are we going? *Clin Transl Sci*. 2010;3:67–68.
22. National Institutes of Health. NIH Reporter. Available at: [http://projectreporter.nih.gov/reporter\\_SearchResults.cfm?icde=6311056](http://projectreporter.nih.gov/reporter_SearchResults.cfm?icde=6311056). Accessed March 1, 2011.
23. Carle A, Simpson L. Identifying child health priorities for comparative effectiveness research from the IOM's Report. *Acad Pediatr*. 2010;10:155–158.
24. Federal Coordinating Council for Comparative Effectiveness Research. *Report to the President and the Congress*. June 30, 2009. Available at: <http://www.hhs.gov/recovery/programs/cer/cerannualrpt.pdf>. Accessed January 9, 2010.
25. Agency for Healthcare Research and Quality. All Recovery Act Projects. Available at: [http://gold.ahrq.gov/projectsearch/external\\_search\\_result.jsp?ARRA=Y](http://gold.ahrq.gov/projectsearch/external_search_result.jsp?ARRA=Y). Accessed February 2, 2011.
26. Botkin J, Anderson R, Staes C, Longo N. Developing a national registry for conditions identifiable through newborn screening. *Genet Med*. 2009;11:176–182.
27. Agency for Healthcare Research and Quality. Researching implementation and change while improving quality: grant awards. In: *Fact Sheet*. Rockville, Md: Agency for Healthcare Research and Quality; 2010. AHRQ Pub No. 10-P012.
28. Gitterman D, Greenwood R, Kocis K, et al. Did a rising tide lift all boats? The NIH budget and pediatric research portfolio. *Health Aff*. 2004;23:113–130.
29. Gitterman D, Hay WJ. That sinking feeling, again? The state of National Institutes of Health pediatric research funding, fiscal year 1992–2010. *Pediatr Res*. 2008;64:462–469.
30. Boat T. The future of pediatric research. *J Pediatr*. 2007;151(5 suppl):S21–S27.
31. Dougherty D, Schiff J, Mangione-Smith R. The Children's Health Insurance Program Reauthorization Act Quality Measures Initiatives: moving forward to improve measurement, care, and child and adolescent outcomes. *Acad Pediatr*. 2011;11(suppl 3):S1–S10.
32. 75 *Federal Register* 75469–75471 (2010) (codified at). Available at: <http://edocket.access.gpo.gov/2010/2010-30262.htm>. Accessed January 12, 2011.
33. Schultz D, Seid M, Stoto M, Burstain J. The Agency for Healthcare Research and Quality's children's health research portfolio. *Matern Child Health J*. 2010;14:1–8.
34. Berdahl T, Owens P, Dougherty D, et al. Annual report on health care for children and youth in the United States: racial/ethnic and socioeconomic disparities in children's health care quality. *Acad Pediatr*. 2010;10:95–118.