Data-Driven Improvement in Care and Patient Outcomes

Also in this issue
- Premature mortality in North Carolina: progress, regress, and disparities by county and race, 2000-2010
- The Perinatal Quality Collaborative of North Carolina’s project to decrease elective deliveries before 39 weeks of gestation
- Special article: Understanding quality improvement is more important now than ever before
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Managing Editor: Kay Downer, MA, 919.401.6599, ext. 36, or kdowner@nciom.org. Assistant Managing Editor: Phyllis A. Blackwell, 919.401.6599, ext. 27, or pblackwell@nciom.org. Editor in Chief: Peter J. Morris, MD, MPH, MDiv, peterjmorrismd@gmail.com. Graphic Designer: Angie Dickinson, angiedesign@windstream.net. Contract copy editors: flora Taylor, Christine Seed. Printer: The Ovid Bell Press, 1201-05 Bluff Street, Fulton, MO 65251, 800.835.8919. Annual Subscriptions (6 issues): Individual, $45.00; Institutional, $65.00; International, $85.00. (Tax is included in subscription rates.)

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North Carolina Institute of Medicine 630 Davis Drive, Suite 100, Morrisville, North Carolina 27560
Phone: 919.401.6599; Fax: 919.401.6899; e-mail: ncmnj@nciom.org; http://www.ncmedicaljournal.com

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These steps are powerful — for you and your whole family.

— Jennifer Landon

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Tar Heel Footprints in Health Care

A periodic feature that recognizes individuals whose efforts—often unsung—enhance the health of North Carolinians

Delton Atkinson, MPH, MPH, PMP

Delton Atkinson, MPH, MPH, PMP, has long promoted the benefits of data-driven decision making and patient care through his work at both the state and national levels. Atkinson graduated from the Gillings School of Global Public Health of the University of North Carolina at Chapel Hill with 2 Master of Public Health (MPH) degrees—in Biostatistics and in Health Policy and Administration—after which he served for 11 years as the director of the North Carolina State Center for Health Statistics (SCHS). In this role, Atkinson was instrumental in developing the center’s capacity to collect and share data through 3 statewide surveillance registries—for immunizations, birth defects, and cancer—and through 3 statewide surveys: the North Carolina School Health Profile Survey, the Pregnancy Risk Assessment Monitoring System (PRAMS), and the Behavioral Risk Factor Surveillance System (BRFSS). These data continue to help tell the story of the health status of North Carolinians.

While serving as the director of the SCHS, Atkinson and several colleagues published a report highlighting the significant health disparities between African Americans and the rest of the state’s population. The report galvanized public health professionals, researchers, and health care providers to prioritize minority health. Around the time the report was published, the General Assembly also established the North Carolina Minority Health Advisory Council to advise the Governor and the Secretary of Health and Human Services. Atkinson remains a strong advocate of minority health and actively supports minority students as they pursue careers in the health professions.

In 1997 Delton joined the National Center for Health Statistics (NCHS) of the Centers for Disease Control and Prevention (CDC). Serving first as the director of the Division of Information Technology, Atkinson focused on managing the NCHS information technology infrastructure while introducing new and emerging technology to meet research needs. Now, as the director of the Division of Vital Statistics, Atkinson’s emphasis is on improving the timeliness and quality of the vital statistics data supplied by the states. He has been the leader in the division’s efforts to build new partnerships within and beyond CDC, to attract funding for mortality surveillance, and to spearhead improvements in the states’ vital statistics systems. With the increasing quantity of data becoming available, Atkinson is a strong proponent of releasing deidentified data sets to the public. “I will never have enough staff to conduct all of the possible analyses to tell all of the stories,” he noted. “We need students, researchers, and others to do this, so [the NCHS] will need to make these data available.” Atkinson’s goal is to release national data sets 9–10 months after the close of each data year.

Today Atkinson splits his time between Research Triangle Park, North Carolina and Maryland. He has dedicated the past 30 years to developing, implementing, and managing data to facilitate data-driven decision making in a constantly changing environment. Assistant Director of the Division of Vital Statistics Kelly Brown lauds, “Mr. Atkinson is relentless in his quest to continually set the bar for the division’s achievement and excellence, but equally careful to set the representative example of achievement and excellence himself.”


Elizabeth Chen, North Carolina Institute of Medicine, 630 Davis Dr, Ste 100, Morrisville, NC 27560 (Liz_Chen@nciom.org).

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The average life span for people in the United States increased by almost 30 years during the 20th century—an average of 3 years per decade [1]. In the first decade of the 21st century, however, only 1.7 years were added to the average life span [2], and that progress was unevenly distributed across population groups and geographic regions. This paper examines longevity using a measure called premature mortality to examine progress and changes in disparities in North Carolina over a recent decade.

Premature mortality is defined here as years of potential life lost (YPLL) before age 75 years, expressed as a rate per 10,000 population (YPLL-75/10K). During the first decade of the 21st century, the premature mortality rate for North Carolina improved substantially, and North Carolina's rank among the states improved modestly. Specifically, the state's premature mortality rate was 843.3 YPLL-75/10K in 2000 but decreased to 735.0 YPPLL-75/10K by 2009, which is a 13% improvement [3]. We were interested to see how the degree of improvement varied among North Carolina counties and between nonwhites and whites.

Premature mortality is a well-accepted indicator of population health because, unlike mortality, it places extra emphasis on early deaths, which presumably might have been prevented [4-10]. It is a main health indicator for the University of Wisconsin, County Health Rankings of the Robert Wood Johnson Foundation [11], and the United Health Foundation's America’s Health Rankings [12]. Healthy People 2020 also uses premature mortality for monitoring general health status [13]. Premature mortality has been described as “the best single proxy for reflecting differences in the health status of states’ populations as measured by both the Healthy People 2000 indicators and the ReliaStar Index” [14]. The Centers for Disease Control and Prevention provides YPLL-75/10K data through its Web-based Injury Statistics Query and Reporting System (WISQARS) [2].

In this paper, we pay particular attention to differences between whites and nonwhites in county-level premature mortality rates. In addition, we examine the causes of premature mortality, both to identify particular diseases that are responsible for premature mortality in a county and to identify counties in which particular causes contribute a disproportionate share of premature mortality.

**Methods**

We calculated the YPLL for individuals who died before age 75 years. Although some studies and surveillance systems use other conceptions of premature mortality and other
age limits to define and calculate it [15-18], our method is the one most commonly used for monitoring population health. YPLL with a cutoff at age 75 years is consistent with rankings now commonly used [11-13], and age 75 years approximates the normal life expectancy in North Carolina (which was 78.1 years in 2010–2012) [19]. Thus, a death prior to age 75 years may be considered an early death. The total YPLL for those who died prior to age 75 years were summed and expressed as a rate per 10,000 population (YPLL-75/10K). The rates were then age-adjusted using the 2000 US standard million population so that counties with different age structures could be compared. Thus measured, premature mortality is a straightforward outcome indicator for overall health and health disparities [8, 20] that can be compared across countries, counties, and states [21]. Our interest was to compare populations and counties in North Carolina.

We calculated YPLL due to premature mortality for each North Carolina county for two 5-year periods: 1996–2000 and 2006–2010 [22]. We calculated YPLL for all individuals, for white individuals, and for nonwhite individuals in each North Carolina county. We then compared the county-level change in the premature mortality rate between the 2 periods (1996–2000 versus 2006–2010). We did not analyze the intervening years. We used 5 years of data rather than smaller time periods because the larger data set provides a more stable estimate of premature mortality at the county level, particularly for small counties.

Vital statistics data from the North Carolina State Center for Health Statistics were downloaded from the Dataverse Web site of the Odum Institute at the University of North Carolina at Chapel Hill [22]. We analyzed the data using 2 racial categories: white and nonwhite. Vital statistics data for North Carolina are classified into the following racial groups: white, black, American Indian, Chinese, Japanese, Hawaiian, Filipino, other Asian, and other nonwhite. We were interested in disaggregating premature mortality by race, but we were limited in how narrowly we could specify the racial categories because we also wanted to analyze the data by county. At the county level, there are often only a small number of individuals in racial groups other than white. Overall, African Americans make up 21% of the state’s population [23], but there is great variation at the county level, and many counties have very small numbers of African Americans, particularly in the western part of the state. For 22 North Carolina counties, African Americans make up less than 5% of the population. For other racial groups, the number is often quite a bit smaller. Robeson County is an exception, as American Indians make up 39% of the population there; for most counties, however, this group makes up less than 1% of the population. Orange County is the only county in which Asians make up more than 5% of the population; in most counties, this group makes up less than 1% of the population. Given the small numbers for individual racial groups, we chose to combine the groups into a single category (nonwhite) so that we could conduct the county-level analysis.

We also chose not to analyze these data in terms of ethnicity. Vital statistics data for North Carolina classify individuals by race, and then separately classify them by Hispanic origin: Cuban, Mexican, non-Hispanic, other Hispanic, Puerto Rican, Central/South American, or unknown. An individual may be white Hispanic, black Hispanic, white non-Hispanic, black non-Hispanic, or any of the many other possible combinations of race and Hispanic origin. We chose not to disaggregate the data in this way because doing so would result in extremely small numbers at the county level. Although Hispanics constitute 8% of North Carolina’s overall population, there are many counties in which less than 5% of the population is Hispanic. Nonetheless, it would be possible to perform a separate analysis of the county-level variability in premature mortality between Hispanics and non-Hispanics, and this would be an interesting analysis for another paper.

For the total and the 2 racial groups, we then counted the number of counties with low, medium, high, very high, or extremely high rates of premature mortality for the 1996–2000 period and compared these numbers with counts for the same categories in the 2006–2010 period; we described these variations with choropleth maps. We also calculated the percentage change in premature mortality rates for each county (ie, the percentage increase or decrease from the 1996–2000 base figure). We grouped counties into those in which total premature mortality decreased by 30% or more, those in which it decreased by 15% to 29.99%, those in which it decreased by less than 15% (but still decreased), those in which it increased by less than 15%, and those in which it increased by 15% or more. We also performed this analysis for each racial group (white and nonwhite) for each county.

We then examined the causes of death that contributed most to premature mortality and calculated the percentage of YPLL attributable to each of the 10 leading causes of death for the state as a whole and for each individual county by race. We did not perform these calculations if there were 20 or fewer deaths attributed to an underlying cause. The purpose of this analysis was to reveal the underlying causes of death responsible for increases or decreases in premature mortality for each county as a whole and for the white and nonwhite populations of each county.

Results

The age-adjusted premature mortality rate for North Carolina as a whole was 886.5 YPLL-75/10K for the 1996–2000 baseline period; this rate declined to 768.4 YPLL-75/10K for the 2006–2010 period. This represents a 13.3% reduction in premature mortality for the state as a whole. There were also substantial reductions in premature mortality in some but not all counties; a high degree of variability was found across the state. For instance, in the 1996–2000 period, Wake County had the lowest rate of premature mortality (644.9 YPLL-75/10K), but the rate...
for Anson County (1,366.4 YPLL-75/10K) was more than double the rate for Wake County. The variability is shown in Figure 1, which clearly reveals the extent, geography, and racial disparities of early deaths.

Although the rate of premature mortality declined for most counties between the 2 time periods, rates were high in eastern counties in both periods. As shown in Figure 1A, the highest numbers of YPLL in 1996–2000 were observed for Robeson, Anson, Edgecombe, and Hertford counties, which were all in the “very high” category (meaning that they had rates of premature mortality in the range of 1,300–1,599 YPLL-75/10K). During this period, there were also 28 counties in the “high” category (with rates in the range of 1,000–1,299 YPLL-75/10K). By 2006–2010 there was only 1 county in the “very high” category, and there were 14 counties in the “high” category, although the geographical pattern was similar to that of the earlier period (Figure 1B). Three western counties—Rutherford, Graham, and Swain—had “high” rates of premature mortality in 1996–2000. By 2006–2010, the rates in Rutherford and Graham counties had decreased to “medium,” but the rate in Swain County had increased to “very high.”

Only 3 counties—Wake, Orange, and Watauga—were in the “low” category (400–699 YPLL-75/10K) in the early period. Ten years later, they were joined by 9 additional counties: Cabarrus, Camden, Chatham, Dare, Davie, Durham, Mecklenburg, New Hanover, and Union. A total of 65 counties had rates in the “medium” category (700–999 YPLL-75/10K) in the early period; they were joined by 8 additional counties in 2006–2010.
When we disaggregated the data by race, premature mortality for the state’s nonwhite population declined by 26.2% over the 10-year period (from 1,375.7 to 1,009.6 YPLL-75/10K). In 58 counties, the premature mortality rate for nonwhite individuals was “very high” or “extremely high” in the 1996–2000 period (Figure 1E). In the early period, the statewide premature mortality rate was nearly 1.9 times higher for nonwhites than for whites (1,375.7 versus 740.5 YPLL-75/10K). Even though the rate for nonwhites declined over 10 years, it remained 1.5 times higher than the rate for whites in 2006–2010. As shown in Figures 1E and 1F, there were 16 counties in which the premature mortality rate for nonwhites was initially in the “extremely high” category, but only 1 county was in that category in the later period (Swain). However, there were still 9 counties in which the rate for nonwhites was “very high” (Robeson, Columbus, Bladen, Lenoir, Northampton, Halifax, Bertie, Vance, and Rutherford). By way of comparison, there were no counties in which the rate for whites was “very high” or “extremely high” in the later period (Figure 1D, and there were only 5 counties in which this rate was “high” (Swain, Scotland, Robeson, Columbus, and Tyrrell).

County-level rates of premature mortality for nonwhites were much higher overall than were rates for whites; although both declined, rates for nonwhites remained well above rates for whites. Indeed, most of the overall decline in premature mortality across the decade is attributable to a reduction in the rates for nonwhites, which have historically been disparately higher. In order to investigate this finding further, we examined percentage change for both racial groups.

Figure 2A shows the percentage change in the county-level premature mortality rate for the entire population (white and nonwhite) across the 2 time periods. The total premature mortality rate declined in 80 counties and increased in 20 counties. There were distinct differences between whites and nonwhites in terms of the percentage change in premature mortality.

The premature mortality rate for nonwhites declined in all but 5 of 100 counties (Figure 2C). In 23 counties, the rate for nonwhites was reduced by 30% or more. This pattern confirms the observation that premature mortality rates for nonwhites exhibited very large declines between 2000 and 2010; however, those rates started out very high and remained high (Figures 1E and 1F). The 5 counties in which the premature mortality rate for nonwhites increased were Swain, Yadkin, Bertie, Jones, and Tyrrell. All of these counties except for Bertie and Jones have very small nonwhite populations so the percentage increase may be due to small changes in actual numbers of premature deaths.

In contrast to the percentage change in premature mortality for nonwhites, the rate for whites in North Carolina declined by only 7.2% between the early period and the late period (from 740.4 to 686.8 YPLL-75/10K). Remarkably, the premature mortality rate for whites increased in 35 counties. Although this increase was less than 5% in 10 counties, there were increases of 5%–10% in 11 counties, increases of 10%–15% in 6 counties, and increases of more than 15% in 8 counties (Figure 2B). Of the counties in which premature mortality for whites increased the most, 4 are located in the eastern part of the state (Tyrrell, Pamlico, Martin, and Craven); 2 are in the Piedmont (Stokes and Vance); and 2 are in the western part of the state (Transylvania and Swain). Given that the state as a whole achieved a reduction in premature mortality, finding counties in which improvement did not occur is important. We were surprised to find so many counties in

![Percentage Change in Rate of Premature Mortality in North Carolina Counties: 1996–2000 Compared With 2006–2010](image)
which the premature mortality rate for whites increased.

The contributions of particular causes of death to premature mortality for whites and nonwhites in each county during the most recent period (2006–2010) are shown in Tables 1, 2, and 3. Cancer is the leading cause of premature mortality for North Carolina as a whole, accounting for 21.2% of all premature mortality (Tables 1, 2, and 3, first row). Heart disease is the cause of another 15% of all YPLL. The other leading causes are unintentional injuries not caused by motor vehicles, unintentional motor vehicle injuries, suicide, homicide, stroke, chronic obstructive pulmonary disease (COPD), diabetes, and kidney disease.

Table 1 shows the percentage contribution of each cause of death to premature mortality for the state’s population as a whole; the 28 counties included in this table are those in which either cancer or heart disease caused a disproportionate share of premature deaths (ie, the contribution to premature mortality for that county was at least 15% greater than for the state as a whole). An expanded table showing data for all 100 counties is available online. The 3 counties with the greatest share of premature deaths attributed to cancer were Granville, Hyde, and Madison. The 3 counties with the greatest share of premature deaths attributable to heart disease were Tyrrell, Mitchell, and Alleghany. In one-third of the state’s counties, a disproportionate share of premature mortality was attributable to nonvehicular unintentional injuries, and in 3 of these counties, the county’s share of premature mortality was almost double the statewide rate.

### Table 1 (Abbreviated)

**Percentage of Premature Mortality in North Carolina Attributable to Various Causes, Statewide and in Selected Counties, 2006–2010**

<table>
<thead>
<tr>
<th>Geographic Region</th>
<th>Cancer (all types)</th>
<th>Heart disease</th>
<th>Nonvehicular unintentional injuries</th>
<th>Unintentional motor vehicle injuries</th>
<th>Suicide</th>
<th>Homicide</th>
<th>Stroke</th>
<th>COPD</th>
<th>Diabetes</th>
<th>Kidney disease</th>
</tr>
</thead>
<tbody>
<tr>
<td>Statewide</td>
<td>21.2</td>
<td>15.0</td>
<td>7.9</td>
<td>7.6</td>
<td>4.7</td>
<td>3.6</td>
<td>2.8</td>
<td>2.8</td>
<td>2.5</td>
<td>1.4</td>
</tr>
<tr>
<td>Alexander</td>
<td>20.4</td>
<td>17.6**</td>
<td>12.1**</td>
<td>8.3*</td>
<td>7.1**</td>
<td>—</td>
<td>2.9</td>
<td>4.0**</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>Alleghany</td>
<td>17.9</td>
<td>20.8**</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>4.3**</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>Anson</td>
<td>19.3</td>
<td>17.3**</td>
<td>6.9</td>
<td>9.8**</td>
<td>4.4</td>
<td>—</td>
<td>4.5**</td>
<td>1.6</td>
<td>3.9**</td>
<td>2.5**</td>
</tr>
<tr>
<td>Avery</td>
<td>24.5**</td>
<td>15.3</td>
<td>10.5**</td>
<td>—</td>
<td>—</td>
<td>3.9**</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>Beaufort</td>
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<td>17.6**</td>
<td>5.5</td>
<td>6.8</td>
<td>4.1</td>
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<td>4.2**</td>
<td>2.6</td>
<td>3.3**</td>
<td>1.8**</td>
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<td>Bladen</td>
<td>17.5</td>
<td>18.3**</td>
<td>8.0</td>
<td>9.9**</td>
<td>—</td>
<td>4.4**</td>
<td>3.0**</td>
<td>4.2**</td>
<td>2.4</td>
<td>1.8**</td>
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<tr>
<td>Carteret</td>
<td>25.3**</td>
<td>17.7**</td>
<td>10.6**</td>
<td>5.8</td>
<td>5.2*</td>
<td>—</td>
<td>2.9</td>
<td>2.9</td>
<td>1.6</td>
<td>1.2</td>
</tr>
<tr>
<td>Caswell</td>
<td>22.8*</td>
<td>18.8**</td>
<td>8.5*</td>
<td>9.9**</td>
<td>—</td>
<td>—</td>
<td>2.5</td>
<td>—</td>
<td>—</td>
<td>—</td>
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<td>Chowan</td>
<td>24.7**</td>
<td>16.2*</td>
<td>—</td>
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Note. COPD, chronic obstructive pulmonary disease.

*This table includes counties in which the premature mortality rate for cancer or heart disease is 15% higher than the rate for North Carolina as a whole. An expanded table containing data for all counties is available in the online version of this article.

*The county’s rate of premature mortality for this cause is 5%–14.9% higher than the rate for North Carolina as a whole.

**The county’s rate of premature mortality for this cause is at least 15% higher than the rate for North Carolina as a whole.

—Data suppressed because fewer than 20 deaths were attributable to this cause.
Motor vehicle crashes were responsible for a disproportionate share of early deaths in 27 counties; the 5 counties with the highest percentages of early death attributable to motor vehicle injuries were Hoke, Bertie, Montgomery, Currituck, and Duplin (see online version of Table 1).

Table 2 shows the causes of premature mortality among whites in North Carolina; the 45 counties included in this table are those that met at least one of the following conditions: the share of premature mortality that was attributable to either cancer or heart disease was at least 15% greater than the rate for the state as a whole; or the overall premature mortality rate for whites was at least 10% higher in 2006–2010 than that had been in 1996–2000. Again, an expanded version of Table 2 showing data for all 100 counties is available online. In addition to cancer and heart disease, noteworthy causes of early deaths among whites were COPD, suicide, nonvehicular unintentional injuries, and motor vehicle crashes.

The 3 counties in which cancer caused the greatest share of early deaths among whites were Perquimans, Washington, and Granville. The 3 counties with the highest shares of premature mortality attributable to heart disease were Mitchell, Alleghany, and Martin. In 14 counties, the premature mortality rate for whites was at least 10% higher in 2006–2010 than it had been in 1996–2000. COPD contributed a disproportionate share to premature mortality in 8 of these 14 counties; suicide contributed a disproportionate share to premature mortality in 6 of these 14 counties; nonvehicular unintentional injuries contributed a disproportionate share to premature mortality in 7 of these 14 counties; and motor vehicle crashes contributed a disproportionate share to premature mortality in 2 of the 14 counties.

As noted above, the premature mortality rate for the nonwhite population declined for the state as a whole; however, this rate increased by 10% or more in 8 counties (Bertie, Jones, Watauga, Yadkin, Dare, Swain, Avery, and Clay). With the exception of Bertie and Jones, however, these 8 counties had very small numbers of nonwhite residents, so the increases in the premature mortality rate were likely due to small fluctuations in the numbers. Although the nonwhite category included African Americans, Asians, Native Americans, and individuals of other races, this group consisted mostly of African Americans, particularly in the eastern region of the state.

Table 3 shows the leading causes of death that contributed to premature mortality for nonwhites. The 47 counties included in the table are those that met at least one of the following conditions: the share of premature mortality that was attributable to cancer or heart disease was at least 15% higher than in the state as a whole; the premature mortality rate was at least 10% greater in 2006–2010 than it had been in 1996–2000; or African Americans comprised at least 35% of the population. The online version of Table 3 includes data for all 100 counties.

The 3 counties in which cancer caused the greatest share of early deaths among nonwhites were Gates, Caswell, and Granville. The 3 counties with the greatest share of premature deaths attributed to heart disease were Surry, Davie, and Rockingham. In 19 counties, African Americans made up 35% or more of the population [23]. In these 19 counties, several causes of death contributed an above-average share of the premature mortality rate for nonwhites: stroke, diabetes, homicide, heart disease, and kidney disease. Surprisingly, these are not the same causes of death that stood out in the analysis of premature mortality for whites.

Stroke caused a disproportionate share of early deaths for nonwhites in 11 of the 19 counties with a high concentration of African Americans. Homicide was responsible for a disproportionate share of early death in 7 of these 19 counties; in Durham and Vance counties, the percentage of premature mortality attributable to homicide was more than double the rate for the state as a whole. Diabetes also contributed a greater share of premature mortality for nonwhites in the counties with large African-American populations; in 12 of these 19 counties, the percentage of premature mortality attributable to diabetes was at least 15% greater than the statewide rate. Finally, the percentage of premature mortality among nonwhites attributable to kidney disease was at least 15% greater than the statewide rate in Cumberland, Durham, Edgecombe, Lenoir, Nash, Vance, and Wilson counties.

Discussion

Although there was substantial improvement in premature mortality in North Carolina over the first decade of the 21st century, the state is far from achieving the premature mortality benchmark set forth in the Robert Wood Johnson Foundation’s County Health Rankings and Roadmaps [24]. The target suggested for states is 531.7 YPLL-75/10K, a figure representing a desired level of outcome at the 90th percentile of states. North Carolina’s 5-year rate for 2006–2010 was 768.4 YPLL-75/10K, which is almost 45% higher than the target rate. In states that are so far away from the benchmark, perhaps the goal should be to achieve a consistent rate of improvement. In Wisconsin, a baseline of at least 1% improvement per year (a standard developed for Healthy People 2020 goals) was used to evaluate the trend in premature deaths [25]. Over the course of a decade, premature mortality in North Carolina decreased by 13.3%, which would be a rate of improvement of slightly better than 1% per year. For nonwhites, the improvement was twice as great—a reduction of 26.6%—but the baseline rate was 160% higher than the County Health Rankings benchmark, and the rate for nonwhites in North Carolina remained almost twice as high as the rate for whites. Can an improvement of 1% per year be sustained in the future?

It is quite remarkable that the reduction in premature mortality for whites was only 7.2% and that premature mortality among whites actually increased in more than one-third of counties. Cancer and heart disease account for some
### Table 2 (Abbreviated).

Percentage of Premature Mortality Among White North Carolinians Attributable to Various Causes, Statewide and in Selected Counties, 2006–2010

<table>
<thead>
<tr>
<th>Geographic region (race)</th>
<th>Cancer (all types)</th>
<th>Heart disease</th>
<th>Nonvehicular unintentional injuries</th>
<th>Unintentional motor vehicle injuries</th>
<th>Suicide</th>
<th>Homicide</th>
<th>Stroke</th>
<th>COPD</th>
<th>Diabetes</th>
<th>Kidney disease</th>
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Note. COPD, chronic obstructive pulmonary disease.

*This table includes counties in which the premature mortality rate for cancer or heart disease is 15% higher than the rate for North Carolina as a whole and counties in which the overall premature mortality rate for whites was at least 10% higher in 2006–2010 than it had been in 1996–2000. An expanded table containing data for all counties is available in the online version of this article.

*Counts listed in **BOLD CAPS** are those in which the premature mortality rate among whites increased 10% or more between 1996–2000 and 2006–2010.

*Rates for all counties are for whites only.

*The rate of premature mortality among whites in this county for this cause is 5%–14.9% higher than the rate for North Carolina as a whole (white and nonwhite).

**The rate of premature mortality among whites in this county for this cause is at least 15% higher than the rate for North Carolina as a whole (white and nonwhite).

—Data suppressed because fewer than 20 deaths were attributable to this cause.
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<td>14.4</td>
<td>3.5</td>
<td>6.3</td>
<td>—</td>
<td>5.6**</td>
<td>2.9</td>
<td>1.3</td>
<td>4.4**</td>
<td>2.8**</td>
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<td>Yadkin**</td>
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</tr>
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</table>

Note. COPD, chronic obstructive pulmonary disease.

*This table includes counties in which the premature mortality rate for nonwhites for cancer or heart disease is 15% higher than the rate for North Carolina as a whole, counties in which the overall premature mortality rate for nonwhites was at least 10% higher in 2006–2010 than it had been in 1996–2000, and counties in which African Americans comprised at least 35% of the population. An expanded table containing data for all counties is available in the online version of this article.

**Counties in which the premature mortality rate for nonwhites for cancer or heart disease is 15% higher than the rate for North Carolina as a whole, counties in which the overall premature mortality rate for nonwhites was at least 10% higher in 2006–2010 than it had been in 1996–2000, and counties in which African Americans comprised at least 35% of the population. An expanded table containing data for all counties is available in the online version of this article.


Note. COPD, chronic obstructive pulmonary disease.

*This table includes counties in which the premature mortality rate for nonwhites for cancer or heart disease is 15% higher than the rate for North Carolina as a whole, counties in which the overall premature mortality rate for nonwhites was at least 10% higher in 2006–2010 than it had been in 1996–2000, and counties in which African Americans comprised at least 35% of the population. An expanded table containing data for all counties is available in the online version of this article.

*Counties listed in BOLD CAPS are those in which at least 35% of the population is comprised of African Americans, based on the 2010 decennial census.


**The rate of premature mortality among nonwhites in this county for this cause is 5%–14.9% higher than the rate for North Carolina as a whole (white and nonwhite).

++The rate of premature mortality among nonwhites in this county for this cause is at least 15% higher than the rate for North Carolina as a whole (white and nonwhite).

—Data suppressed because fewer than 20 deaths were attributable to this cause.
of the increase in premature mortality among whites. Was the increase due to health behaviors, access to care, or quality of care? Access to preventive services and to timely and appropriate medical care should be investigated in counties with a disproportionate share of premature mortality. In addition, cause-specific culprits of premature mortality were found to include COPD, suicide, nonvehicular unintentional injuries, and motor vehicle crashes. COPD in particular begs for attention. It has become the third leading cause of death in the United States [26], and smoking is the primary cause of COPD [27]. Smoking is also a primary cause of lung cancer [28]. Are smoking rates in these counties not decreasing, or are they not decreasing sufficiently? If so, the public health community should increase efforts to help people quit smoking and should undertake more effective educational campaigns to convince people not to start smoking. Physicians must do a better job of diagnosing COPD and warning patients about the risks of smoking. Public health professionals conducting community health assessments should also focus attention on suicide prevention, injury prevention, and quality of trauma services in counties in which these causes contribute a disproportionate share to premature mortality.

In their community health assessments and interventions, counties with large nonwhite populations should consider focusing on the diseases and traumas that contribute disproportionately to early deaths among the county’s population as a whole and among nonwhites in particular. Although programs and services to address heart disease and cancer are important for nonwhites, attention should also be given to stroke, diabetes, and kidney disease—and to the underlying risk factors for these conditions. In addition, programs that address social pathologies that underlie homicide could have a dramatic effect on YPLL, because many homicide victims are young people.

The data presented here are the result of an initial attempt to get more detailed information from the available mortality statistics. The major limitations of this analysis are the definitions of race and ethnicity, the presence of populations that are too small to be analyzed, and the unreliability of the reported underlying cause of death. Death certificates may overreport heart disease as a cause of death [29], and specification of the underlying cause of death becomes more complicated as the number of comorbidities increases. Cause of death is also likely to be less accurate for older individuals with multiple chronic conditions [9]. That is one reason to define YPLL in terms of deaths before age 75 years. However, death certificates are the best data that is consistently gathered that we can use to compare populations. Another limitation is that we have not examined differences between men and women. Kindig and Cheng recently reported that female mortality rose in 42.8% of US counties between 1992 and 2006 [30]; analysis of trends in premature mortality by sex is needed. We are also unable to report time series trends due to space limitations.

Future analyses should look more closely not only at specific causes of premature mortality but also at the age groups affected by particular causes. Also, although premature mortality is a good summary measure, it does not tell the whole story. Why do we see so much variation in early death among counties with large nonwhite populations? And why has there been so little progress among whites in certain counties?

These data lend support to the suggestion by Olshansky and colleagues that life expectancy may be declining in the United States in the 21st century [31], possibly because of obesity. Is that what we are seeing in North Carolina? Is the decline in overall improvement in premature mortality (and the increase in premature mortality in some counties) the result of obesity and its effect on multiple systemic chronic diseases? If so, is this trend the result of what people eat, how much they eat, sedentary lifestyle, or smoking? Continued and more precise surveillance of mortality and premature mortality by age group, race, and sex is necessary. NCMJ

Katherine Jones, PhD social research specialist, Center for Health Systems Research and Development, East Carolina University, Greenville, North Carolina.

Christopher J. Mansfield, MS, PhD director, Center for Health Systems Research and Development, and professor, Department of Public Health, East Carolina University, Greenville, North Carolina.

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The Perinatal Quality Collaborative of North Carolina’s 39 Weeks Project: A Quality Improvement Program to Decrease Elective Deliveries Before 39 Weeks of Gestation

Kate Berrien, James Devente, Amanda French, Keith M. Cochran, Marty McCaffrey, Bethany J. Horton, Nancy Chescheir

BACKGROUND Despite long-standing guidelines from the American College of Obstetricians and Gynecologists that call for avoiding elective births prior to 39 weeks of gestation, elective deliveries make up almost one-third of US births occurring in weeks 36–38. Poor outcomes are more likely for infants born electively before 39 weeks than for those born at 39 weeks. The Perinatal Quality Collaborative of North Carolina (PQCNC) undertook the 39 Weeks Project in 2009–2010 with the aim of reducing the number of early-term elective deliveries in North Carolina hospitals.

METHODS Participating hospitals (N = 33) provided retrospective data on all early-term deliveries and created new policies, or amended or enforced existing policies, to accomplish the project’s goals. Project activities included in-person learning sessions, regional meetings, webinars, electronic newsletters, a secure extranet Web site where participating hospitals could share relevant materials, and individual leadership consultations with hospital teams. Hospitals submitted monthly data to PQCNC, which provided ongoing training and data analysis.

RESULTS Elective deliveries before 39 weeks of gestation decreased 45% over the project period, from 2% to 1.1% of all deliveries. The proportion of elective deliveries among all scheduled early-term deliveries also decreased, from 23.63% to 16.19%. There was an increase in the proportion of patients with documented evidence of medical indications for early delivery, from 62.4% to 88.2%.

LIMITATIONS No data were collected to determine whether outcomes changed for patients whose deliveries were deferred. The project also depended on each hospital to code its own data.

CONCLUSIONS The PQCNC’s 39 Weeks Project successfully decreased the rate of early-term elective deliveries in participating hospitals.
Methods

The PQCNC leadership team included a neonatologist, a perinatologist, a quality improvement specialist, an obstetric nurse coordinator, a project manager, and a family support specialist; the input of these individuals to the project was equivalent to 2.5 full-time-equivalent staff members. An advisory board representing constituent organizations, health care providers, and consumers in North Carolina provided guidance to the leadership team. An expert panel of North Carolina obstetricians and nurse leaders also provided guidance and support for the project. This panel was selected from clinical leaders at hospitals that had already successfully undertaken quality improvement efforts to address late-preterm and early-term elective deliveries (36 0/7 to 38 6/7 weeks). The institutional review board (IRB) at the UNC School of Medicine reviewed this initiative and determined that it did not constitute human subjects research and therefore did not require IRB approval.

Hospital recruitment. All 88 hospitals in North Carolina with maternity services were invited to participate in this project. Participating hospitals agreed to collect and submit deidentified data to PQCNC and to create a project team that included physician, nurse, and administrative champions. Each team was encouraged to engage patients and families as advisers in their efforts. The only participation costs to hospitals were internal costs for data collection and submission.

Forty-one hospitals agreed to participate in the project; however, 3 of these hospitals joined the initiative late and submitted data retrospectively, and 5 other hospitals were unable to complete the project due to reductions in resources. The remaining 33 hospitals submitted 9 months of data on schedule and are represented in this analysis. These 33 hospitals, which perform approximately 60% of all deliveries in North Carolina, include most of the academic and tertiary centers in the state, as well as regional centers and rural community hospitals. Hospital delivery volumes ranged from 100 to more than 7,000 deliveries annually.

Project activities. Activities and tools included 3 in-person learning sessions, regional meetings, monthly webinars, a patient experience video, a weekly electronic newsletter, a secure extranet Web site for sharing relevant literature and materials from participating hospitals, and individual consultations with hospital teams. Learning sessions included didactic content from medical experts and patients, reports from participating teams about effective strategies, and time for teams to work individually on their hospital’s action plan. Regional meetings facilitated informal exchange of information among participating teams. Monthly webinars addressed data collection methodology, provided updates on data trends, and allowed discussion of challenges and successes.

Rather than prescribe a single course of action for all teams, PQCNC encouraged each team to develop its own action plan for decreasing the rate of elective deliveries before 39 weeks, so that each plan could reflect local needs and dynamics. Although PQCNC endorsed a statewide goal of eliminating elective deliveries before 39 weeks, each hospital team established site-specific goals based on its current performance and circumstances. During learning sessions, regional meetings, and webinars, PQCNC asked hospitals to share their strategies and practices for achieving the project’s goals.

Data collection. Each hospital was assigned a numeric code and submitted deidentified data for the period October 2009 through June 2010; data were submitted to PQCNC using a secure Web portal. Data elements included gestational age of the fetus at admission, use of amniocentesis, indication for delivery, mode of delivery, induction methods, birth weight, infant length of stay, neonatal complications, and maternal complications. Data were submitted for all planned deliveries—defined as scheduled cesarean sections and all inductions of labor—that occurred when the fetus’s gestational age was between 36 0/7 and 38 6/7 weeks. In addition, hospitals submitted overall totals for deliveries, scheduled cesarean sections, and inductions of labor for fetuses of all gestational ages.

The expert panel assigned each indication for delivery to 1 of 6 categories (A through F) based on their consensus regarding the appropriate management of patients with that indication; a seventh category (G) was created to capture other indications written in by the site (Table 1). The project aimed to reduce or eliminate category F, which includes deliveries explicitly identified in the chart as elective—that is, those with no indication for early delivery or with a primary indication of “repeat cesarean section.”

Data reporting. Hospitals received monthly reports from PQCNC. These reports included the number of scheduled deliveries occurring before 39 weeks of gestation; use of amniocentesis to determine fetal lung maturity; mode of delivery (cesarean section or vaginal delivery) for patients admitted for induction; number of cases with a primary indication of “elective,” which included cases with no documented indication or with “repeat low transverse cesarean section” as the primary indication; and the percentage of all indications that were supported by objective evidence using the standard definitions provided by the project’s expert panel.

Hospitals were also given in-depth quarterly reports that showed the distribution of primary indications for scheduled deliveries among the 7 categories for each institution as well as for the entire group of participating hospitals. Quarterly reports identified scheduled deliveries associated with maternal complications, neonatal complications, or both, and reports gave the percentage of cases in each category for which amniocentesis was performed. Hospitals were encouraged to use these data to revise their action plans and to enlist the support of key stakeholders within each institution. Local solutions were shared during monthly proj-
Telephone calls and during meetings that were held in response to specific inquiries. These solutions were collated but were not analyzed, so they are reported qualitatively.

Statistical analysis. Random effects models were used to assess the relationship between variables of interest while accounting for the many facilities with a random effect component. For binary variables, such as elective delivery or presence of neonatal complications, a generalized linear mixed model (PROC GLIMMIX, PROC NLMIXED) was used. For continuous variables, such as gestational age and birth weight, a linear mixed effects model (PROC MIXED) was used. All components of the analysis were performed using SAS 9.2 software (SAS Institute, Cary, North Carolina).

Results

Decrease in elective deliveries. The 33 hospitals participating in the project collectively decreased early-term elective deliveries over the 9 months of the study from 2% to 1.1% of all deliveries; this represents an overall decline of 45% (Figure 1). Among all scheduled deliveries occurring between 36 0/7 and 38 6/7 weeks of gestation, the percentage of elective deliveries declined from 23.63% to 16.19%, which represents a decline of 31.5% (P = .002; Figure 2). Figure 3 shows monthly changes in the number of early-term deliveries by indication category (as defined in Table 1). Declines were noted in category F—the category for elective deliveries, which was the target for this project—and in category G, which included “other” indications for delivery.

Repeat elective cesarean sections. The primary driver of elective early-term deliveries was the category of repeat elective cesarean sections, which represented 70.6% of elective early-term deliveries and 14.1% of all scheduled deliveries before 39 weeks of gestation (Figure 4). In comparison, elective inductions accounted for only 5.9% of early-term scheduled deliveries.

Gestational age. Gestational age was greater for elective early-term deliveries than for early-term deliveries that were medically indicated (P < .001). The median gestational age for elective early-term deliveries was 38 5/7 weeks, whereas the median gestational age for medically indicated early-term deliveries was 37 6/7 weeks.

Evidence of medical indications for early delivery. There was a significant increase over time in the proportion of medically indicated, scheduled, early-term deliveries for which objective evidence of a medical indication was documented in the medical record (P < .001). In the first month of the project, 62.4% of primary medical indications for scheduled early-term deliveries were supported by objective evidence; by the end of the project, 88.2% of medical indications were supported by such evidence.

Neonatal complications. Among elective early-term deliveries, 8.4% were associated with a neonatal complication, and 4.1% resulted in admission to the newborn intensive care unit (NICU). In comparison, 17.3% of medically indicated, scheduled, early-term deliveries were associated with a neonatal complication, and 11.7% of such deliveries resulted in admission to the NICU.

Amniocentesis. The overall rate of amniocentesis was low across the study period but did increase by a statistically significant amount, from 6.9% at the start of the project to 8.4% by the end of the project (P = .05). There was no significant difference in use of amniocentesis between elective
early-term scheduled deliveries compared with those that were medically indicated ($P = .63$).

**Maternal complications.** Overall, maternal complications occurred infrequently during the project. As expected, early-term deliveries that were medically indicated were associated with a higher rate of maternal complications (5.8%) compared with elective early-term deliveries (0.9%). The proportion of scheduled early-term deliveries with maternal complications did not change significantly over time ($P = .14$).
HOSPITAL STRATEGIES. Hospital interventions varied across facilities and included changes to hospital policies, consensus agreements by members of the hospital’s obstetrics department, education of physicians and nurses, and a peer-review process for elective early-term deliveries. Some hospitals required that the departmental chair or a local perinatologist approve an early-term scheduled delivery unless there was a clear, documented indication. Hospitals became more rigorous in requiring information from providers who wished to schedule deliveries before 39 weeks of gestation, asking them to provide the medical indication for the delivery, supporting documentation, and the criteria used to establish gestational age.

DISCUSSION

The 39 Weeks Project successfully decreased early-term elective deliveries over the 9-month period of the initiative. Rates of elective early-term deliveries and overall early-term births declined, without an increase in neonatal morbidity, suggesting that declines were accomplished by eliminating many elective early-term births, improving classification of early-term births that were medically indicated, and prolonging pregnancy in some women with medically or obstetrically complicated deliveries. Despite this success, elective deliveries still account for almost 17% of all deliveries occurring between 36 0/7 and 38 6/7 weeks of gestation in the participating hospitals.

Consistent with other published findings [16-18], many hospitals reported that a “hard stop” at the point of scheduling was the most effective method for reducing elective deliveries before 39 weeks of gestation. A “hard stop” occurs when the scheduler may not schedule a patient for delivery before 39 weeks of gestation without appropriate indications and supporting data. Several hospitals established a peer-review process specific to early-term elective deliveries or used an existing obstetric peer-review committee to ensure that specific feedback was given to any provider who performed an elective delivery before 39 weeks of gestation without an amniocentesis documenting lung maturity.

Given the impact of cesarean sections on the rate of scheduled deliveries before 39 weeks of gestation, we were not surprised to find that issues related to scheduling of surgery dominated the list of barriers noted by participating hospitals. Hospitals with dedicated obstetrical operating rooms could control the scheduling process more easily than could hospitals in which cesarean sections were performed in the hospital’s main operating rooms. Barriers also reflected lack of availability of 24-hour, dedicated obstetric anesthesia coverage.

One challenge to reducing the rate of early-term elective cesarean sections involved “block scheduling” of surgical time, in which all planned surgical procedures for the week are performed at a set time. Providers described performing a scheduled repeat cesarean section once the patient had completed 38 weeks of gestation in order to avoid scheduling cases too far into the 39th week of gestation, to avoid the possibility of an emergent cesarean delivery secondary to active labor. However, no PQCNC hospitals reported an increase in unscheduled cesarean sections as a result of prohibiting repeat elective cesarean sections before 39 weeks of gestation.

Research relevant to the PQCNC initiative and all materials from learning sessions and webinars were shared on an extranet Web site available to each hospital. PQCNC phy-
cian leaders facilitated discussions at several hospitals about the relevant medical issues, particularly when clinicians put up significant resistance to the implementation of changes. Inclusion of hospital administrators in hospital-based quality initiatives was also important, because it helped to defuse potential doctor-nurse conflicts around scheduling and to standardize processes across each institution.

Patient requests were perceived to be an important driver of early-term elective deliveries. The fact that many institutions across North Carolina participated in this initiative reduced providers’ fears that patients would abandon their practice and switch to a practice more willing to offer an early elective delivery. Physician champions noted that a hospital-wide standard prohibiting elective deliveries prior to 39 weeks of gestation helped prevent this scenario. Finally, hospitals found it easier to implement changes as part of a broader initiative; they were better able to influence provider groups that were resistant to policy changes by emphasizing that the hospital was attempting to adhere to standards set “by the state.”

The March of Dimes provided a brochure explaining the risks of elective early-term deliveries [19], which PQCNC distributed to childbirth education programs, provider offices, and triage patients who requested a scheduled delivery due to the discomforts of late pregnancy. Providers used the brochure to educate patients during early pregnancy about their policies, so that expectations would be clear well in advance of the patient’s due date. This study found a significant increase in the provision of objective evidence supporting medical indications for early delivery, which suggests that providers improved their documentation, that only those deliveries that were truly medically necessary were performed, or both. Clear documentation tends to decrease legal risk for providers and hospital personnel. From a financial perspective, improved documentation for a delivery with complications may lead to a more appropriate diagnosis-related group (DRG) code and to increased reimbursement. Some deliveries should occur prior to 39 weeks of gestation, and accurate documentation of medical, fetal, and obstetrical complications can facilitate appropriate timing of scheduled early deliveries, as well as appropriate reimbursement. In 2011 the National Institute of Child Health and Human Development and the Society for Maternal-Fetal Medicine held a workshop to synthesize the available information about conditions that may necessitate medically indicated late-preterm or early-term births, and an article was subsequently published outlining what was learned about the optimal timing of delivery for specific conditions [20]. That information can help clinicians and hospitals avoid the problems that can arise when efforts to avoid elective early-term deliveries have the unintended consequence of preventing medically indicated early-term deliveries; these problems are highlighted in a 2012 article by Clark and colleagues [21].

The 1.5% absolute increase in the use of amniocentesis suggests that the 39 Weeks Project heightened attention to the ACOG guidelines stating that early-term elective deliveries should not be performed in the absence of test results indicating fetal lung maturity [1, 2]. However, amniocentesis was not performed on a substantial number of the women who did undergo early-term elective deliveries, and the observed change in use of amniocentesis was probably not clinically significant.

Demonstration of improved maternal and neonatal outcomes, with no increase in potentially avoidable complications, can help motivate the obstetric team to effect and

![Graph of Cesarean Sections as a Proportion of All Early-Term Scheduled Deliveries, All Medically Indicated Deliveries, and All Elective Deliveries at Hospitals Participating in the 39 Weeks Project of the Perinatal Quality Collaborative of North Carolina, October 2009 Through June 2010]
sustain the changes necessary to avoid scheduled early elective deliveries. Obstacles include work/life balance, pressure from patients, concerns about complications that could potentially be avoided by earlier delivery, difficulty in scheduling, and lack of access to 24-hour anesthesia services in smaller hospitals.

Financial incentives and effective management of resources and costs may also motivate change. Community Care of North Carolina (CCNC), a care management plan for North Carolina’s Medicaid recipients, recently implemented a pregnancy “medical home” model [22]. To qualify as a pregnancy medical home and receive financial benefits, practices must agree to avoid elective deliveries prior to 39 weeks of gestation, in addition to meeting other requirements. The Joint Commission and the National Quality Forum now include the early-term elective delivery rate among their core measures for hospital accreditation, and this rate is included in publicly reported data [14, 15]. Numerous other states have adopted policies or launched multihospital initiatives to reduce the number of early-term elective deliveries [11, 16, 23-25]. Participating teams observed that challenges in scheduling medically indicated procedures were eased by eliminating elective early-term procedures. Similarly, other initiatives have reported decreased length of stay, improved patient throughput in labor and delivery, and decreased hospital costs [10, 11].

One strength of this initiative is its scope; participating facilities perform nearly 60% of deliveries in North Carolina. Also, the PQCNC data were collected specifically for each eligible case; we did not rely on administrative data sets or patient samples. An important limitation of the project is that no data were collected on patients whose babies were delivered after 39 weeks of gestation; we were therefore unable to determine whether outcomes changed for patients whose deliveries were deferred. Another limitation is that each hospital coded its own data. Also, fewer than half of the North Carolina hospitals with obstetrics services participated in this study; reasons for declining to participate were not collected, and participating and nonparticipating hospitals were not compared. Finally, successful strategies for preventing early-term elective deliveries at the hospital level were not collected in a formal manner.

Conclusion

This project demonstrates the ability of North Carolina hospitals and their obstetrics departments to work collaboratively and to effectively conduct an important quality improvement project with the potential for substantial improvements in neonatal outcomes, decreased use of health care resources, and improved care as a result of better documentation. Although the participating hospitals achieved a substantial collective decline in the rate of early-term elective deliveries, almost 17% of early-term deliveries were still elective at the end of the project. In a multistate trial with similar goals, Oshiro and colleagues [18] were able to reduce early-term deliveries from 27.8% of all deliveries to 4.8% of all deliveries over 12 months. Despite the successes achieved in the PQCNC 39 Week Project, there remain challenges: diminishing the rate of early-term elective births even further, sustaining the efforts of the participating hospitals, and spreading the successes of the project to hospitals that did not choose to participate.

Kate Berrien, RN, BSN, SM maternal health projects coordinator, Perinatal Quality Collaborative of North Carolina, Chapel Hill, North Carolina; and pregnancy medical home project manager, Community Care of North Carolina, Raleigh, North Carolina.

James Devente, MD obstetric project medical director, Perinatal Quality Collaborative of North Carolina, Chapel Hill, North Carolina; and associate professor, Brody School of Medicine, East Carolina University, Greenville, North Carolina.

Amanda French, RNC-OB, MSN, CNS clinic initiative coordinator, Perinatal Quality Collaborative of North Carolina, Chapel Hill, North Carolina; and nursing coordinator, Prenatal Diagnostic Center, Duke University Health System, Durham, North Carolina.

Keith M. Cochran, MLT (ASCP), MS, PMP, LSSBB program manager, Perinatal Quality Collaborative of North Carolina, Chapel Hill, North Carolina.

Marty McCaffrey, MD director, Perinatal Quality Collaborative of North Carolina, Chapel Hill, North Carolina; and neonatologist, Department of Pediatrics, School of Medicine, University of North Carolina at Chapel Hill, Chapel Hill, North Carolina.

Bethany J. Horton, BS research assistant, Department of Biostatistics, Gillings School of Global Public Health, University of North Carolina at Chapel Hill, Chapel Hill, North Carolina.

Nancy Cheseoir, MD obstetric project medical director, Perinatal Quality Collaborative of North Carolina, Chapel Hill, North Carolina; and professor, Department of Obstetrics and Gynecology, School of Medicine, University of North Carolina at Chapel Hill, Chapel Hill, North Carolina.

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POLICY FORUM

The Dawn of Big Data

Introduction

My first personal computer was an Apple II+, which had about as much computing power as my current sports watch. I then upgraded to a Macintosh computer that had less computing power than my current cellphone. These computers were useful for word processing but could not do much else; there were no spreadsheets, Internet, or e-mail. Then I learned biostatistics and began to explore the mysteries that lie within large data sets, which could be revealed by precisely asking the right questions. At the time, performing these analyses involved punching holes onto cards that were then loaded into a mainframe computer; answers to one’s query—and error messages—came hours later.

For most of us, the integration of computers into health care has been a slow journey from paper charts inscribed in undecipherable script to databases of electronic medical records. Now, as we enter the era of big data, health care is poised to take another leap, one that would have been unimaginable only a few years ago. This issue of the NCMJ explores some applications of big data, its benefits, and its limitations.

One benefit of big data is that it provides tools that can help individual practices discern how well they are doing in caring for their patients. Years ago I asked local pediatricians to review a sample of charts to see if children really received all of their periodic immunizations on schedule. Before conducting the chart review, all of the pediatricians had been sure their immunization rates were just fine, but this small study showed otherwise. Today, the North Carolina Immunization Registry can show in seconds what previously took us hours to prove.

With 1 case, I can claim that something is true “in my experience”; with 2 cases, I can say it is true “in my series”; and with 3 cases, I can say it is true in “case after case after case.” With big data, however, we can be even more accurate: We can say that something is true in a carefully defined population with a precisely calculated level of certainty.

Previously clinicians practiced medicine by using personal data to guide individual care; now, population data can better inform such care not only by answering our questions but also by raising new ones. This is the dawn of a big day that will lead to improved care for our patients, our practices, and our community. NCMJ

Peter J. Morris, MD, MPH, MDiv
Editor in Chief
The growing adoption of electronic medical records and advances in health information technology are fueling an explosion of new health data. Expectations are high that new data resources will guide the transformation of the health care industry and positively influence population health. There have been challenges and opportunities at every turn, and progress has been slow, but mounting evidence suggests that better use of data is moving health care in the right direction.

The considerable attention being paid to advances in health information technology (HIT) and health care reform suggest that the United States is in the midst of a health care revolution. Economic incentives offered by the Centers for Medicare & Medicaid Services (CMS) have resulted in huge increases in the adoption of electronic medical record (EMR) systems; the percentage of physicians with EMR systems that allow them to record notes in patient records increased from 44% to 73% between 2009 and 2012 [1]. Similarly, health insurance and payment reforms are forcing a shift from fee-for-service, volume-based care to outcomes-based, value-driven care; in the latter paradigm, care is often provided by patient-centered medical homes (PCMHs) or accountable care organizations (ACOs), potentially using payment arrangements such as shared savings programs or bundled payments. These new models of care are driving the need for new data systems, and public demand for transparency and consumer engagement are also growing rapidly. Together these changes have the potential to rapidly and dramatically transform the health care system. Although some of these HIT concepts may seem radical, real-world implementation has been lengthy and often painful, and the transformation is actually more evolutionary than revolutionary.

Although this transformation is not yet complete, we already have more data, more types of data, and greater access to data than we have ever had before. How is this “big data” environment changing health care? Are we using data to help us chart the best course for change? Is our use of data making patients healthier, reducing the cost of care, and improving patients’ experience in the health care system [2]? How is the health care industry using HIT and newly developed data capacities to reshape and improve the health care system in North Carolina? These are the questions addressed by the distinguished group of authors, health care providers, and data analytics experts who contributed to this issue of the NCMJ.

**Background**

Although health care reform is a political hot potato, the need to make fundamental changes in our health care delivery system is undeniable. This is particularly true with regard to data. The health care system needs better data so that we can understand what needs to change, and so that we can evaluate the success of changes that are currently in progress. Technology is already an integral part of virtually every aspect of our lives, and health care can no longer afford to lag behind. Emerging concepts such as big data, informatics, data visualization, health information exchanges (HIEs), telehealth, and mobile health are now mainstream thinking in HIT, and the public eye is upon us. Our educational institutions and training programs are producing a new generation of health care professionals who grew up with information technology and expect to use it in their workplaces. Users’ appetite for HIT and the public’s acceptance of it are also improving significantly as health care applications grow, multiply, and mature.

Ironically, much of the information technology currently being deployed in health care is not new. Other industries—such as banking, insurance, entertainment, and even grocery stores—have built innovative ways of collecting and using existing data that create value for their individual businesses and their industry. For example, the online retailer Amazon.com has such large and sophisticated data resources that the company can tweak the font used in an online consumer offer and measure the effect of that change within minutes [3].

Many trends are converging to move HIT forward, but one of the most important is the concept of meaningful use. CMS’s federally funded Electronic Health Record Incentive Program provides financial payments to eligible Medicare and Medicaid providers (physicians and hospitals) who meet meaningful use requirements by demonstrating that they use certified EMR systems effectively. Core objectives for eligible providers in the program [4] are listed in Table...
TABLE 1.
Objectives for Stage 2 Meaningful Use for Eligible Professionals Participating in the Electronic Health Record (EHR) Incentive Program of the Centers for Medicare & Medicaid Services

Core objectives

1. Use computerized provider order entry for medication, laboratory, and radiology orders directly entered by any licensed health care professional who can enter orders into the medical record per state, local, and professional guidelines.

2. Generate and transmit permissible prescriptions electronically.

3. Record the following demographic information: preferred language, sex, race, ethnicity, and date of birth.

4. Record and chart changes in height/length and weight (no age limit) and blood pressure (for patients aged 3 years or older); calculate and display body mass index (BMI); and plot and display growth charts, including BMI, for patients aged 0–20 years.

5. Record smoking status for patients aged 13 years or older.

6. Use clinical decision support to improve performance in treating high-priority health conditions.

7. Provide patients the ability to view online, download, and transmit their health information within 4 business days of the information being made available to the eligible health professional.

8. Provide clinical summaries for patients for each office visit.

9. Protect electronic health information created or maintained by the certified EHR technology through the implementation of appropriate technical capabilities.

10. Incorporate clinical lab-test results into the certified EHR technology as structured data.

11. Generate lists of patients by specific conditions to use for quality improvement, reduction of disparities, research, and outreach.

12. Use clinically relevant information to identify patients who should receive reminders for preventive or follow-up care and send these patients the reminders, per patient preference.

13. Use clinically relevant information from the certified EHR technology to identify patient-specific education resources and provide those resources to the patient.

14. The eligible professional who receives a patient from another setting of care or provider of care or believes an encounter is relevant should perform medication reconciliation.

15. The eligible professional who transitions a patient to another setting of care or provider of care or refers a patient to another provider of care should provide a summary care record for each transition of care or referral.

16. Have the capability to submit electronic data to immunization registries or immunization information systems, except where prohibited, and in accordance with applicable law and practice.

17. Use secure electronic messaging to communicate with patients regarding relevant health information.

Menu objectives

1. Have the capability to submit electronic syndromic surveillance data to public health agencies, except where prohibited, and in accordance with applicable law and practice.

2. Record electronic notes in patient records.

3. Have the capability to access imaging results, consisting of the image itself and any explanation or other accompanying information, through the certified EHR technology.

4. Record patient family health history as structured data.

5. Have the capability to identify and report cancer cases to a public health central cancer registry, except where prohibited, and in accordance with applicable law and practice.

6. Have the capability to identify and report specific cases to a specialized registry other than a cancer registry, except where prohibited, and in accordance with applicable law and practice.

Source: Adapted from information on the Centers for Medicare & Medicaid Services Web site [4].

1. This incentive program is driving EMR adoption, setting standards for EMR application development, and making clinical information digital and sharable. Technology-enabled EMR systems, meaningful use requirements, payment reform, market transparency, and consumer choice are rapidly changing the rules of the game. As Helm-Murtagh states in her commentary in this issue, “The pressure to reduce costs and improve outcomes is ... generating new models of care and payment ... which require the integration and analysis of clinical and financial data” [5]. In the reformed health care marketplace, successful health care organizations must embrace new technology and be able to use their data wisely to create value for their business and their customers.

Big Data

A great deal has been said about “big data,” which has been described as high-volume, complex, unstructured bits of digital information that can be mined for relevant content. As Duke University psychologist Dan Ariely observed, “Big data is like teenage sex: everyone talks about it, nobody really knows how to do it, everyone thinks everyone else is doing it, so everyone claims they are doing it” [6]. Use of big data in health care is poorly defined, and wild promises have been made about what it can deliver, but in my view big data is not where we should be focusing our first efforts in the quest to remake our health care system. As Groves and colleagues have noted [7], “The big-data revolution is in its
early days, and most of the potential for value creation is still unclaimed."

That said, this issue of the NCMJ includes excellent examples of North Carolina providers who are embracing the notion of using large-scale databases to better understand their businesses. Community Care of North Carolina (CCNC) has a large database of Medicaid claims, pharmacy information, and other data from its 14 care networks statewide, and it uses these data to “intelligently [target] the subpopulation of patients who are most likely to benefit from care management support” [8]. Algorithms and predictive modeling enable CCNC to proactively identify the patients on whom care management intervention will have the greatest impact and to rapidly communicate that information to providers. Doing so has improved the health of the patients served by CCNC networks and has saved millions of dollars for the state’s Medicaid program.

The research and pharmaceutical industries have long depended on data for product development and safety. The introduction of new technology, the ability to easily add more real-time clinical data, the growth in networks of providers, and the addition of patient-generated information will only increase the usefulness of such data. In a commentary in the current issue, Menius and Rousculp point out that “to support the approval of new medicines, the pharmaceutical industry has conducted thousands of clinical studies, resulting in data that can be reanalyzed to compare the outcomes of different treatments or to identify patient subgroups with varying efficacy or safety profiles” [9]. Other sectors of the health care industry are just beginning to learn how powerful data analytics may prove to be.

Big data is an attempt to make sense of diverse health and behavioral observations by connecting seemingly unrelated events to outcomes. Some HIT experts believe that the speed of data gathering and the variety of data sources included in an analysis are more important than the volume of data. Others have obtained positive results by slicing and dicing huge historical data sets using new questions and new analytic techniques. One thing we know for certain is that the adoption of EMRs, the use of clinical HIEs, success in mapping complex genetic sequences, and the use of electronic disease registries mean that the amount of health data now being generated on a daily basis is staggering, and it will continue to grow exponentially. According to Eric Schmidt, chief executive officer of Google, “the world creates 5 exabytes of data every two days. That is roughly the same amount created between the dawn of civilization and 2003” [3].

**Connected Health**

Developing the concept of *connected health* is perhaps even more important than amassing huge databases of newly available health information. How can we take the information that already exists in patient charts, observations by members of the health care team, and knowledge about patients’ lives and use that information to make better and timelier health care decisions? The answer is that we must do a better job of securely and appropriately sharing existing information among multiple providers and patients. HIT and HIEs enable providers to use this information to make better decisions at the point of care, when they can have the greatest impact on the patient’s health. These are not elaborate new insights into new data or complex algorithms using advanced analytics; rather they are existing bits of personal health information that can be shared among members of the patient’s care team. For example, clinicians can provide significantly improved care if they know which medications have been prescribed for the patient, their potential adverse effects, whether the patient has been filling the prescriptions on time, and when and why the patient has been hospitalized; clinicians can also benefit from having faster and easier access to results of all laboratory tests performed for the patient, including those ordered by other providers in the same or other facilities.

In this issue, James describes how one North Carolina accountable care organization is using low-tech approaches to transmit data and drive change [10]. HIT is making connections easier and is expanding the scope of relevant information that the provider has at hand when making treatment decisions. HIT is making it possible to collect, validate, and integrate more data about how a patient lives, and these data have direct implications for the patient’s care and health. In another commentary, Dayton describes how new technology is being deployed by the North Carolina Immunization Registry to create a bidirectional electronic interface that will enable a provider’s EMR system to communicate directly with the registry [11]. This connection will allow the provider to see a patient’s complete vaccine history and to know which additional vaccines are recommended.

**Patient Engagement**

Consumer-mediated HIEs and patient-generated health information will ultimately play a significant role in the data systems currently under development. It has been firmly established that the majority of a person’s health status is determined by the individual’s lifestyle choices, his or her environment, and the level of family/community support available [12]. Thus it is increasingly important for health care providers to understand what happens to their patients outside the health care delivery setting. Providers and patients must work together in new ways, and technology can assist in this effort. Successful practices across North Carolina have adopted a PCMH approach to providing care for their patients. In their sidebar on quality improvement at Asheville Medicine and Pediatrics, Schau and Rokaw note that their objective for patients is that “they have an understanding of their care plan and of ways of collaboratively managing their health” [13]. A transformed health care system will rely on enhanced patient engagement to improve health.
New technologies are making it possible to gather and record information about the patient outside the office. Mobile health devices such as FitBit exercise bands (FitBit, Inc., San Francisco, California) and remote patient monitoring are growing in popularity, and these devices enable monitoring and quantitative data to be collected almost anywhere and anytime. Mobile disease management is an area in which personal health data is projected to grow rapidly. It is predicted that by the year 2018, 24 million people will use some sort of personal electronic diabetes management application, most likely on their smartphones [14]. As technology increasingly puts the patient in the center of the health information universe, trusted providers will gain unprecedented access to all aspects of a patient’s life—family, environment, behaviors, and real-time health status.

Of course, this expanded sharing of personal health information will not happen if patients are not comfortable with the security of this information or if they do not agree with how it will be used on their behalf. In his commentary in this issue, Juengst explores the inherent conflict between privacy and transparency [15]. He makes the point that if we truly want to build a learning health system [16], we must address complex issues of trust, confidentiality, and patient participation. Also in this issue, Califf suggests that perhaps it is time to reexamine the division between clinical practice and research [17]. Should there be an expectation of patient involvement in research design and implementation, as well as an expectation to participate in data sharing?

The meaningful use standards for eligible providers and hospitals not only require that providers have technology that can engage patients—such as Web portals and electronic communications—but also require that patients actually use this technology. The meaningful use deadlines for meeting certain thresholds in patient engagement have been relaxed; however, the need to substantively engage the consumer will be crucial for success as we move forward. Soon consumers will demand transparency, choice, and control of their own personal health information. The assumption is that patients will be willing to share their information if they perceive that doing so will help them and if they believe that the system will protect their privacy and security.

Population Health Management

Population health management is another term that often comes up in discussions about health care reform. It is commonly used to describe a data-driven process for understanding a group of patients with a specific set of circumstances (e.g., a certain disease) and deciding how best to manage their health in a value-based reimbursement system. The term “population health management” can be confusing because it means different things to different people, depending on what goal they hope to achieve with the data.

Governmental public health is founded on principles of population health management. Public health professionals have long tracked specific conditions across a broad population base over time in order to identify trends or threats and then determine actions to improve the health status of the affected population. In this issue, Bruckner and Barr make the case that population health is now an essential part of health care, and they provide examples of how a local public health department partnered with community hospitals to identify patients with diabetes and to lower the burden of disease using community-based services [18].

Identifying patients with diabetes who might benefit from community-based services might be considered population health surveillance, but population health management in the context of the current health care reform movement is more focused on “active” population health management—the ability to effect change using the data obtained by such surveillance. HIT experts describe 2 types of population health management that are emerging in the new, better-integrated health care market: care management and performance management. The difference between the 2 is that the users of the data have different goals. In care management, data is used by providers, care coordinators, and patients to better manage a patient’s health risk. In performance management, the users are health care administrators, chief medical officers, and chief technology officers who are using data to improve the care delivery process [19]. Both purposes are valid, and those involved in care management and performance management often rely on the same or overlapping data sources. However, they use different applications and analytics to answer their questions, and the lack of coordination between the 2 user groups, often in the same organization, is a potential problem.

As James observes in his commentary [10]:

To achieve the ACO ideals of population health and to become truly accountable for cost, quality, and the experience of patients, we must identify, implement, mine, and analyze data in a new way. Data must now encompass a much broader representation of the continuum of care than was previously possible in the American health care system, which has traditionally been extremely fragmented.

Peters and colleagues explain in their commentary [20] that one of the most effective tools for improving population health management is an all-payer claims database (APCD). An APCD allows health policy professionals and decision makers to better understand health care utilization and costs across a broad range of populations. Many states are building APCDs in response to the need for comprehensive, multipayer data, which is required by health care reform and the new models of care. APCDs typically include data derived from medical claims, pharmacy claims, eligibility files, provider files, and dental claims from both private and public payers. The majority of APCDs are built under the strength of a state mandate. There are currently 14 states with existing APCD systems and 26 states with APCDs in various stages of development [18].

North
Carolina is one of only 10 states that do not currently have plans for an APCD.

Conclusion

An examination of the current state of data-driven care in North Carolina can lead to several conclusions. First, we face the problem of data overload—the new HIT environment is producing more data than the health care industry is prepared to deal with at this point. Specific examples of best practices exist, but they are often born out of a specific need and use only a subset of data capacity. As HIT matures and evolves further, the life cycle of health care decisions will become shorter as dramatic improvements occur in the time it takes to move through the information continuum—from multiple data points from a variety of sources, to useful information, to enhanced data analytics, to clinical insights, and ultimately to the best decisions made in the right places at the right time.

Second, most health care providers would benefit from making better use of the data they already have to improve outcomes. The focus should be on building connections with members of the care team and with patients rather than relying too much on elaborate new technologies. HIT is necessary for the successful practices of the future, but it will take time for it to develop and become a part of the provider work flow.

In addition to technology, much of our ability to create healthy outcomes in an accountable health care delivery system will depend on our ability to engage patients. Few things are more important to the effective delivery of health care services than a relationship between patients and providers that is built on a strong foundation of trust. As we take advantage of all of the new technology that enables us to collect and share information about our lives and our health, we must make sure that we do not lose the patient’s trust. This means that the right legal and social framework must be in place to protect the patient and to allow for appropriate sharing.

Finally, it is time for North Carolina to seriously explore building an APCD. North Carolina is well positioned for transformation of its health care delivery system. The state is endowed with smart, committed providers; nationally recognized health care institutions; leading academic medical centers and professional training programs; a strong public health infrastructure; and industry leaders in technology, pharmaceuticals, and health research. We have all of the necessary components, but our success will depend on how well we work together and learn from one another as we create the health care system the citizens of North Carolina deserve.

References


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J. Steven Cline, DDS, MPH vice president for strategic partnerships, Community Care of North Carolina, Raleigh, North Carolina.
Community Care of North Carolina’s 14 networks use data analysis to provide relevant solutions that are responsive to unique regional environments. This article describes some of the ways that these networks use data to improve patient self-management, to meet providers’ needs, to improve quality of care, and to control costs.

The sheer volume of information that is available from claims, electronic health records (EHRs), health information exchanges, and real-time hospital data feeds is staggering [1]. Many who wade into this sea of information either drown in the waves or quickly head back to the safety of dry land, but Community Care of North Carolina (CCNC) has learned to surf these waters and is offering a helping hand to others who are trying to navigate the currents.

CCNC uses data in a number of different ways. CCNC’s data formula directs care managers to the right patient at the right time so they can provide life-changing support and education. The data formula also allows CCNC quality improvement (QI) staff to identify primary care practices in which QI efforts will have maximum impact, and this same information is offered through the CCNC provider portal so that practices can direct and measure their own QI efforts. Pharmacists in each of the 14 CCNC networks compile information from multiple sources into a concise form that providers can use to prevent drug interactions, duplicate scripts, or the prescription of contraindicated drugs. CCNC networks have also used EHR data from providers to create visual aids that make it easy to identify trends, to define subpopulations, and to refine work flows and processes in providers’ practices.

Because CCNC is made up of 14 networks across North Carolina, solutions for data delivery and analysis need to be local, relevant, and responsive to each unique regional environment and its resources. Described below are some of the ways in which CCNC networks are enhancing patient self-management and helping providers to analyze data, discover trends, and improve quality of care. Through these efforts and others, CCNC saved nearly $1 billion in the 4-year period 2007–2010 [2].

The CCNC Informatics Center

The CCNC Informatics Center is an electronic data exchange infrastructure that is connected to both statewide and local health care quality initiatives sponsored by the North Carolina Department of Health and Human Services Division of Medical Assistance, the Centers for Medicare & Medicaid Services (CMS), the North Carolina State Health Plan for teachers and state employees, Blue Cross and Blue Shield of North Carolina, and other group health plans of private employers. Currently, the Informatics Center contains health care claims data provided by Medicaid and other participating payers, including Blue Cross and Blue Shield of North Carolina and the North Carolina State Health Plan, as well as health information about program participants obtained directly from health care providers and care managers. Data sources include eligibility files and paid claims for the statewide Medicaid population; Medicare and commercial paid claims for beneficiaries in regional programs; laboratory data from LabCorp and Solstas Labs; real-time admission, discharge, and transfer data from 52 North Carolina hospitals (as of January 2014); pharmacy data from Surescripts and Express Scripts; abstracted data from primary care medical records; and structured data from patient or caregiver interviews as documented by CCNC care managers. This information is accessed by the CCNC networks to identify patients who may need care coordination; to facilitate disease management, population management, and pharmacy management initiatives; to communicate key health information across settings of care; to monitor cost and utilization outcomes; to monitor quality of care; and to provide performance feedback at the patient, practice, and network levels [3].
Using Data to Direct Care Coordination and Patient Engagement Efforts

The savings potential of population management programs depends on intelligently targeting the subpopulation of patients who are most likely to benefit from care management support, “right sizing” the intervention, and identifying care opportunities in real time—in other words, engaging with the right patient at the right time in the right setting with the right care team. CCNC uses data to proactively identify the patients for whom care management interventions are most likely to yield savings, as well as to efficiently connect these patients with local resources that can address their specific needs across care disciplines and delivery settings.

Predictive modeling keeps efforts focused on the patients who are most likely to benefit from a care manager’s help (Figure 1). CCNC has made a conscientious effort to employ nurses, social workers, pharmacists, and physicians in positions where they can practice at the highest level commensurate with their license, which has led to the formation of teams that put actionable information in the care manager’s hands at the right time to maximize the impact of each interaction with the patient. Interacting with the patient at home, in the hospital, at the primary care provider’s office, and by telephone are all part of a formula for patient engagement that allows patients and providers to avoid any treatments and medical expenses that do not contribute to improvements in the patient’s health [4].

Tara Robinson and Lori Banks, deputy directors of Community Care of Wake and Johnston Counties, explain that the data available in the Informatics Center allows their network care managers to apply a “boots on the ground” approach to population health management. The care manager team is able to effectively drive change at all levels of care by providing actionable information. At the hospital level, for example, care managers might target interventions to specific patients with high rates of emergency department (ED) utilization. Robinson notes that care managers can use Informatics Center data to inform advanced practice paramedics which patients are high ED users “so that they can divert [these] patients to a particular ED for consistency of treatment.” Banks adds that

the reports that are generated in the CCNC Informatics Center are created using algorithms that incorporate previous billing and diagnoses. This ... produce[s] reports that give the network the ability to target transitional care patients who are at the highest risk for readmission.

At the practice level, network team members can have conversations with providers about these patients, which in
We initially worked on our quality projects for 1 hour per week, but we quickly realized that more time was needed and set aside 4 hours per week. Now we devote 1 full day per week to the administrative processes and reports that support the system changes needed to measure and continue our improvement. We have monthly quality meetings with our physicians and another monthly meeting with a quality improvement consultant from MAHEC, and these meetings have helped us to clarify rules and regulations. Our MAHEC consultants have provided encouragement, resources, and tools, and they helped us engage the physicians early in the process.

Ultimately we knew that the entire staff would need to be involved, so we began sharing our EHR reports at monthly staff meetings. These meetings helped us develop new policies and procedures that made it possible to improve care for our patients. As the practice has made progress, each person on our staff has played an integral role: Staff members sign up patients for our electronic portal to improve communication, perform previsit planning, provide transitional care, and engage patients by conducting motivational interviewing. The physicians also work in collaboration with patients to set up individual care plans. All of these processes are fluid and may change based on patients’ needs. Our objective for patients is that they have an understanding of their care plan and of ways of collaboratively managing their health.

Quality is a long-term commitment. The requirements turn allows providers to have conversations with patients about their ED use. At the patient level, a care manager can provide telephonic and in-person contact and care coordination for the individual [5].

Using Data to Direct Provider Engagement and QI Efforts

Data analytics are used in a similar way to identify variations in care at the provider, practice, and community levels in order to pinpoint opportunities for focused system-level improvements in care delivery. CCNC QI staff use data from the Informatics Center to direct their work with more than 1,600 participating practices statewide and to engage local partners in collaborative solutions.

Two CCNC regions—Community Care of the Lower Cape Fear and Southern Piedmont Community Care—recently developed a stratification tool that QI staff members can use to prioritize which practices and which projects are of highest importance, and this tool has since been made available to all 14 CCNC networks. When prioritizing which practices to work with intensively on QI projects, QI teams use CCNC’s risk-adjusted key performance indicators to identify practices whose patients have higher rates of hospitalization, higher rates of ED use, or greater-than-expected costs given their illness burden. The QI team further prioritizes practices that have the most room for improvement and that serve the largest numbers of patients. Aimee Donaton, QI director for Community Care of the Lower Cape Fear, observes

We then also must weigh a practice’s capacity to work on quality improvement and to implement changes. Practices are made up of people, and the stages of change must be observed just as they are with patients. You cannot make a practice change if the individuals in that practice are not ready to embrace a change.

Deb Aldridge, QI director of Southern Piedmont Community Care, shared this sentiment, noting that it is easy for providers to get so absorbed in seeing individual patients that they lose sight of the practice’s patient population as a whole. The QI staff helps providers interpret data so that they can improve their metrics specifically for Medicaid patients, but the changes a practice makes in response to these data tend to have a positive effect on other subpopulations of patients as well.

Using tools from the Informatics Center, QI professionals in CCNC networks across North Carolina help providers interpret data, discover trends, and construct focused rapid-cycle projects that lead to improvements in the quality of care and reduced costs. The large quantity of information...
that is available can be overwhelming for providers in primary care practices, but CCNC QI teams help providers to find a starting point and to create practical improvement projects based on interventions that have worked in other practices of similar size and composition.

Using EHR Data to Look at the Whole Practice

Historically CCNC’s primary data source has been participating payers, but CCNC networks are increasingly responding to requests from practices that want to use their EHR data to analyze trends across patient populations. For example, Community Care of Western North Carolina recognized that practices want to incorporate EHR data when they consider how to improve processes, and the network responded by forming a team consisting of a QI specialist, an EHR applications specialist, and a clinical data specialist. This team created effective tools that practices can use to analyze trends in their EHR data; specifically, these tools use the clinical quality measure reports that many practices already generate to demonstrate their compliance with CMS’s meaningful use requirements (Figure 2). Practices often do not have the time to extract and analyze EHR data; by helping practices determine where to make changes that result in improvements, CCNC networks are stepping up to meet emerging needs.

Data Convergence in the Comprehensive Medication Review

CCNC network pharmacists use multiple data sources to create patient summaries as part of CCNC’s Pharmacy Home Project. Unlike medication lists, this comprehensive and detailed review includes information from pharmacies, including the patient’s prescription refill history; information from health information exchanges; patient self-reports; real-time data from hospitals; and information from the patient’s medication cabinet. This comprehensive medication review summarizes data for the primary care provider, so that providers have timely and accurate information to aid them in making the best clinical decisions for the patient (see Appendix 1; online version only). Megan Rose, director of pharmacy services for Community Care of the Lower Cape Fear in southeastern North Carolina, describes the comprehensive medication review as “a true picture of what the patient is actually doing” with his or her medication regimen, which is a more complete picture than the one gained from the patient’s self-report or from a medication list.

This is an example of how CCNC networks compile information that is too fragmented in its raw form for providers to compile on their own. In the emerging Care Triage pilot project, which is a partnership between CCNC and GlaxoSmithKline, patients are being assessed for risk of future hospitalizations and adverse drug events based on current medication information and real-time hospital data. Care Triage will ultimately give providers population management tools based on predictive modeling.

On the Horizon

As the focus of care delivery shifts from volume to outcomes, provider organizations are increasingly taking on greater financial responsibility for maintaining the health of

![FIGURE 1. How Community Care of North Carolina Uses Health Care Cost Data to Identify Patients for Care Management Outreach](image-url)

Note. Each dot represents the cost of each patient’s potentially preventable health care, and placement of the dots indicates the cost of that individual’s health care during the preceding 12 months. To determine which patients are most likely to benefit from care management outreach, every patient in the population is assigned to a clinical risk cohort according to a hierarchical model using standard claims data (including inpatient, outpatient, physician, and pharmacy data history). The highest-cost outliers in patient risk cohorts #1 and #2 would likely benefit from targeted care management that focuses on potentially preventable hospitalizations or emergency department visits, because their health care costs are greater than those of others in the same cohort; under conventional flagging methodology, these patients might have been missed. In contrast, care management would likely have minimal impact on most of the patients in patient risk cohort #3, although all of these people might have been flagged using conventional flagging methodology.
the populations they serve. Adopting a value-based population management model requires organizations to develop new capabilities for understanding the needs of populations and for developing targeted care management and QI interventions. Annette DuBard, CCNC’s senior vice president for informatics and evaluation, believes that the goal for the future should be “the triple aim of better outcomes, better patient experience, and lower costs … [facilitated] through hosted analytical support for whole patient populations, using real-time data from multiple sources.”

As more and more CCNC-participating practices access the North Carolina Health Information Exchange, they will have the immediate benefit of real-time data exchange and secure communications with other providers, connectivity to the state’s immunization registry and to electronic lab reporting, and a mechanism for reporting clinical quality measures to meet CMS meaningful use requirements. CCNC will soon be able to provide practices with a more adaptable business intelligence dashboard interface to support population management efforts for their whole patient panels. These dashboards, which will be in a secure hosted environment, will include clinical disease registries and tools to track measures that are pertinent to patient-centered medical home recognition, meaningful use, the Physician Quality Reporting System, and uniform data system reporting. This resource will offload the challenging work of gleaning usable information from new technology, thus creating economies of scale for safety-net providers and independent practices.

As we navigate these exciting waters, we greet new opportunities to “lift all boats” in health care QI for the benefit of North Carolina as a whole. NCMJ

Randy Barrington, MBA quality improvement facilitator, Community Care of North Carolina, Raleigh, North Carolina; and lead quality improvement coordinator, Community Care of the Lower Cape Fear, Wilmington, North Carolina.

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Growth in Health Care Data Causing an Evolution in the Pharmaceutical Industry

J. Alan Menius Jr, Matthew D. Rousculp

A health care ecosystem is evolving in which all stakeholders will need to work together, apply new technologies, and use disparate data sources to gain insights, increase efficiencies, and improve patient outcomes. The pharmaceutical industry is leveraging its experience and analytics capabilities to play an important role in this evolution.

For more than 60 years, the pharmaceutical industry has focused on research into data-driven care—a process that is fundamental in drug development and has seemingly remained unchanged [1]. Scientists within industry continue to work alongside those in academia, government, and clinical practice to study factors that play important roles in biological function, disease progression, and the mechanisms of action of potential medical interventions. This work has produced terabytes of information about genetics and molecular biology to further our understanding of diseases and to identify and validate new biological targets for the next generation of medicines [2].

Results from randomized controlled clinical trials remain the primary source of information that regulators use to decide whether and under what circumstances to make a new medicine available to patients. To support the approval of new medicines, the pharmaceutical industry has conducted thousands of clinical studies, resulting in data that can be reanalyzed to compare the outcomes of different treatments or to identify patient subgroups with varying efficacy or safety profiles. By design, clinical trials are conducted according to strict protocols, so that a medicine’s safety and efficacy can be determined. However, these study designs are not sufficient to answer all of the questions raised by clinicians or population-based decision makers (eg, formulary committees). Because of this necessity, the pharmaceutical industry is now investing in disparate real-world health care data sources, such as administrative claims, electronic health records, pragmatic trials, Internet patient portals, and registries.

The future promises to provide additional sources of data that can inform both pharmaceutical research and clinical care. Initiatives that have arisen from the Patient Protection and Affordable Care Act—which involve changes in health care delivery, changes in payment models, and a focus on quality—promise to provide a continuous source of big data relevant for understanding appropriate patient care. Over the past 3 years, the number of physicians using electronic medical records has grown substantially, with nearly three-quarters of office-based physicians using electronic records to support some form of patient care [3]. New technologies applicable to pharmaceutical research are also being tested, including wearable devices for patients, which allow patients to have less frequent study visits while providing researchers the ability to monitor patients in real time.

Efforts to Support Patient Care

While tremendous advances continue to be made in the process of drug discovery and development, the pharmaceutical industry is also focusing on using its data and analytics experience to support patient care in the changing US health care environment. For example, GlaxoSmithKline announced a collaborative analytics arrangement with Community Care of North Carolina (CCNC) in late 2013. The goal of this arrangement is to combine the strengths of these 2 organizations in order to allow health care providers to take a real-time approach to identifying potential barriers to the delivery of high-quality care. This combined initiative takes a “small data” approach, meaning that it uses health information analytics and patient-centered data to develop a predictive model that can identify patients who are at high risk of future negative outcomes, such as rehospitalization [4].

In 2013 GlaxoSmithKline also announced a data transparency program that allows greater access to deidentified patient-level data from clinical trials [5]. The goal of this program is to provide significant opportunities for additional research in the hope that giving researchers and clinicians access to patient-level clinical trial data will allow them to replicate, challenge, or combine data in ways that will facilitate scientific progress and improved patient care. Greater transparency will help ensure that the data provided by clinical research participants are used to maximum effect in the future.
creation of knowledge and understanding.

In an additional effort, GlaxoSmithKline has committed its analytics resources as part of the Observational Medical Outcomes Partnership (OMOP). OMOP is an interdisciplinary research group that is tackling the fundamental analytical task of identifying the most reliable methods for analyzing big data drawn from heterogeneous sources, such as electronic health record systems and insurance claims. OMOP was founded in 2007 by the Foundation for the National Institutes of Health as a public-private partnership and has since transitioned to the Reagan-Udall Foundation for the Food and Drug Administration [6].

Individually these endeavors may seem unconnected, but they share a common thread—the need to adapt to the changing US health care environment. Because the pharmaceutical industry has expertise in medical analytics, a focus on protecting patient-level data, and a need to better understand the true effectiveness of treatments, the industry is working in many areas to ensure that data are accessible and that appropriate analytics are available to realize the full potential of these data.

Best Practices in Data-Driven Care

The experience of conducting hundreds of studies using real-world health care data has presented challenges, but it has also provided us with several best practices. Although the following list is not exhaustive, we believe these are some important areas of concern and best practices for those interested in data-driven care:

**Involve analytics experts and guard against misinformation.** Because data have varying degrees of robustness, analytics experts should be involved to prevent the production and communication of misinformation. In the absence of analysts with appropriate quantitative expertise, researchers who analyze real-world data may be fooled by false but seemingly plausible findings. Even when trained analytics experts are engaged in this research, there is a danger that findings may not be reproducible. Thus the production of reproducible results will be an extremely important way of guarding against the dissemination of misinformation [7].

**Tune the analysis system.** It is very important to empirically test assumptions regarding databases, study design, and analysis methods together—as components of an analysis system—in order to fully understand the inherent biases that may impact results when studies use large observational databases. Initiatives such as OMOP and efforts funded by the Patient Centered Outcomes Research Institute (PCORI) and the Office of the National Coordinator of Health System Technology (ONC) demonstrate that further research is required to improve the accuracy of studies that rely on observational data [8].

**Decide who owns health care data.** Our society is still trying to answer questions regarding how we should use health information and who should have access to it. This cultural debate is readily apparent as patients, physicians, and government agencies consider who owns a patient’s health care history and what ethics may come into play with regard to use of that data. The recent decision by the US Food and Drug Administration that required the genetic testing company 23andMe to temporarily halt the sales of its genetics kits to patients [9] is an example of this struggle.

**Ensure that patients and key stakeholders will benefit.** To ensure that high-quality data will be captured, systems should ensure that whoever is providing the data will benefit from making it available. For example, patients who provide data describing their condition should receive information that helps them to better understand or manage their health. Similarly, health information systems should reward health care professionals for inputting high-quality data by instantly giving them information that will help guide their decision making, making their job easier or more efficient. Companies such as PatientsLikeMe have pioneered this approach to collecting data, and they are now using those data to achieve new insights about diseases such as amyotrophic lateral sclerosis [10].

**Make health care data available.** While randomized clinical trials will continue to be an important tool for conducting research, if we are to reach our goal of optimizing real-world outcomes for all patients, then data that capture the health care journey of those patients must be made available for research. Only by analyzing those combined data will we then be able to accurately make patient-specific predictions. In order to ensure the relevance of our work, we must create an environment of data transparency and data access, an expectation of free communication of study results, and a commitment to increasing patients’ involvement in research. To overcome these challenges and reach our goals, we must foster a health care ecosystem in which all stakeholders work together to find ways of practically and responsibly using technologies and information to drive new efficiencies, to improve patients’ understanding of their current health status, and ultimately to improve health outcomes.

The concept of getting all stakeholders involved is not new. In fact, PCORI’s primary research agenda is geared toward creating patient-centered systems. Patient-centered research networks—collaborations among digitally enabled health care systems, academics, and patient groups—are being fostered by federal investments that are intended to facilitate more timely and robust patient-centered outcomes research. Examples of such networks include PCORI’s clinical data research networks; the National Institutes of Health (NIH) Health Care Systems Research Collaboratory; and the Electronic Data Methods Forum for Comparative Effectiveness Research, which is an initiative of the Agency for Healthcare Research and Quality. In the not-too-distant future, we may see “machine learning systems that will allow clinicians to match a patient’s electronic health record directly to RCT [randomized controlled trial] and observational study data sets for better, individualized therapeutic
decisions” [11]. Through this lens, we seem tantalizingly close to the goal of the Institute of Medicine of the National Academies, which is to create a learning health care system in which “clinical decisions will be supported by accurate, timely, and up-to-date clinical information and will reflect the best available evidence” [12].

Make health care data relevant. In addition, as the United States and other countries move to value-based systems for delivering health care, the pharmaceutical industry is adapting by seeking to better understand the kind of research that patients, clinicians, payers, and policymakers will need to make more informed decisions. The collaboration between GlaxoSmithKline and CCNC leverages CCNC’s considerable experience in providing analytically based community care. CCNC’s strengths are in developing real-time interventions that guide patient engagement and can be accessed by a range of health care providers in different settings; such interventions are particularly useful at key transition points in care, such as when a patient is discharged from the hospital. GlaxoSmithKline is contributing its expertise in comprehensive medication management and its knowledge of data analytics and information technology systems. This project will provide the appropriate health care providers with an analytic tool and suggested interventions that are likely to facilitate better patient engagement and improved patient outcomes. The goal of the project is to assist these health care professionals in recognizing and responding to medication-related problems that often lead to poor adherence with the prescribed treatment regimen.

The desire to better understand how to provide appropriate health care to the right patient at the right time drives innovative research design. GlaxoSmithKline’s initiatives and similar work in academia, government, and industry are part of the broader effort to create a learning health care environment. When making high-quality data available for use, it is important to protect patient privacy and to ensure ethical behavior. We must therefore work together to find ways to use these data while also guarding against the promotion of misinformation. Ultimately the key to getting better data will be to get patients involved and to make sure that they are the final beneficiaries of these efforts. NCMJ

Matthew D. Rousculp, PhD, MPH senior director, Comparative Effectiveness Research and Health, GlaxoSmithKline Research and Development, Research Triangle Park, North Carolina.

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References
The Road to High Performance Is Paved With Data

Jeffry G. James

Data is a necessary component of any organization’s move toward accountability. This commentary describes Wilmington Health’s use of high-tech and low-tech data sources in its journey to succeed as an accountable care organization. This commentary also discusses shortcomings in the availability of data and the lack of transparency regarding cost and quality.

Wilmington Health, PLLC—a physician-owned, physician-governed, fully integrated multispecialty group practice with more than 160 providers—is a good example of health care reform in the trenches. With a focus on the demonstration of quality, Wilmington Health is leading the way in providing excellent health care, reducing costs, and improving the patient experience.

Wilmington Health has provided health care to the residents of Southeastern North Carolina for more than 40 years and has been instrumental in leading the region toward accountability. It developed the region’s first accountable care organization (ACO) and is a participant in the Medicare Shared Savings Program (MSSP) of the Centers for Medicare & Medicaid Services (CMS). Wilmington Health has demonstrated year-on-year improvement in nearly every MSSP measure of performance—including both cost and quality—and it has performed significantly better than other ACOs in its MSSP cohort (the 104 other ACOs that started the program on January 1, 2013). Wilmington Health maintains a partnership with Blue Cross and Blue Shield of North Carolina that includes an ACO agreement for shared savings, and last year Wilmington Health shared the stage with Kaiser Permanente as a recipient of the American Medical Group Association’s prestigious Acclaim Award, which recognizes health care organizations’ progress in moving toward a delivery model that is safe, effective, patient-centered, timely, efficient, and equitable.

Wilmington Health’s drive to become a high-performing health system has necessitated a comprehensive, multifaceted, wholesale organizational transformation. This type of transformation has required the development of leadership at all levels and has been mobilized through a formal data-driven program of change. The program of change followed by Wilmington Health is well described in a 1993 McKinsey Quarterly article by Dichter and colleagues, titled “Leading Organizational Transformations” [1]. This program of cultural transformation includes 3 main elements: top-down direction setting, bottom-up process improvement, and core process redesign. Top-down direction setting is established by Wilmington Health’s 7-member physician board of directors, which is responsible for setting and monitoring the strategic direction of the organization and for communicating that direction to the group. Bottom-up process improvement comes from Wilmington Health’s use of a Lean management philosophy, which considers any expenditure of resources that does not improve value for patients, employers, or payers as wasteful and subject to elimination. This philosophy requires that the people doing the work must be the ones to improve the work. The third element, core process redesign, is where the other 2 elements come together. As the Dichter article states, the goal of core process redesign is “to achieve breakthrough improvements in cost, quality, and timeliness” [1].

Central to all 3 of these elements is the need for data and measurement systems. Some of these needs are obvious; for example, the board of directors clearly needs data in order to make course corrections in the strategic direction of the organization. Likewise, systems cannot be improved if they cannot be measured. The data derived from measurement helps those who are involved in bottom-up process improvement to understand the waste in the system and to develop countermeasures to remove it. These types of data are often derived from observation, information technology platforms, and trial and error within the confines of the system being evaluated.

In contrast, the data required for core process redesign differs both from the data used by the board to set the organization’s strategic direction and from the data used by Lean teams to drive waste from the system. Much of the data needed for core process redesign does not yet exist, either at Wilmington Health or in the health care system as a whole. To achieve the ACO ideals of population health...
and to become truly accountable for cost, quality, and the experience of patients, we must identify, implement, mine, and analyze data in a new way. Data must now encompass a much broader representation of the continuum of care than was previously possible in the American health care system, which has traditionally been extremely fragmented.

The power of core process redesign comes from bringing cross-functional elements together across the continuum of care in a collaborative, data-driven model. The industry is making great strides in collecting and coalescing data from multiple sources, and innovations in technology are coming at a rapid rate. Many ACOs have progressed to their second electronic medical record (EMR) system and no longer view this system as a mirror image of the paper chart; rather, it is now viewed as a data warehouse that is connected to their mission, vision, and strategic plan. EMR data and claims data can now be linked to provide a clearer picture of cost and quality across a single health care system. These same data can also be used in predictive modeling that can greatly enhance an organization’s ability to focus resources in the areas that are most amenable to improvements in cost and quality.

However, there are still some shortcomings in the technology that inhibit collaboration across the continuum of care and prevent true patient engagement. Health information exchanges are still in their infancy, and they are just now starting to develop in a way that will allow the types of activities mentioned above to be accomplished over a broad range of disparate electronic systems. The good news is that this technology is moving forward quickly, and solutions are imminent. Attempts to use data to accomplish the Institute for Healthcare Improvement’s Triple Aim objectives—improving the patient experience, improving the health of populations, and reducing per-capita costs [2]—have been limited not only by technology but also by the unwillingness of various stakeholders to make cost and quality information transparent. The lack of transparency in cost data reduces patient engagement by keeping health care consumers in the dark regarding a significant component of their health care decision making. As economist Harold Miller noted in a 2012 article published by the Center for Healthcare Quality and Payment Reform [3], this lack of transparency in cost data also prevents health care providers from developing new payment systems.

Wilmington Health has transformed itself by implementing various systems that are allowing it both to redesign its internal systems and to enhance its interactions with external data environments. As might be expected, several high-tech approaches have been implemented. For example, point-of-service analytical tools allow for real-time notification of gaps in evidence-based care when a patient presents to any location in the Wilmington Health system, and an application developed for handheld devices (smartphones) can be used to inform a transition-of-care coordinator about a high-risk discharge. In addition, a new system integrates practice management with the EMR system, and a population health tool that has been bolted onto this integrated system incorporates claims data from payers, provides feedback, and facilitates predictive modeling for population health initiatives.

In addition to these high-tech tools, Wilmington Health uses several low-tech methods to transmit data and drive change. For example, emergency department (ED) providers now have an “easy button” they can use to leave a voicemail message about a patient who needs to be seen, and Wilmington Health guarantees that that patient will be seen the next day. Other low-tech efforts can be seen in the handwritten graphs that line the walls of Wilmington Health, which are used to measure and report daily progress on several important initiatives.

Wilmington Health also uses both internal and external working groups to analyze data and provide feedback and comparisons. One of these groups is the internal “pilots group,” which reviews the organization’s many ongoing experiments. This group vets the data and adjusts the experiments before they are rolled out to the entire organization, to increase the likelihood of early acceptance of the data. To obtain external validation of the data process, Wilmington Health has joined the Anceta Collaborative Data Warehouse, which was established by the American Medical Group Association. Including such notable organizations as the Mayo Clinic and the Henry Ford Health System, this collaborative meets twice yearly to transparently share data, and it normalizes these data across its 18 member organizations. Whichever organizations are performing well on any particular measure openly share their best practices, and the collaborative engages in transformative discussions that help shape the overall direction and implementation of evidence-based medicine.

As a result of implementing and applying both data solutions and cultural transformation, Wilmington Health and its ACO partners have enjoyed some remarkable improvements. Nearly every core measure of cost and quality has improved over the past several years, and Wilmington Health continues to perform significantly better than other organizations in its ACO cohort.

For example, Figure 1 shows the number of hospital admissions per 1,000 patient-years in Wilmington Health’s MSSP from 2010 through 2013, as well as the mean for the other ACOs in the MSSP cohort at the end of 2013. Between 2010 and 2013, Wilmington Health reduced its number of admissions per 1,000 patient-years by 19%, and it had 28% fewer admissions per 1,000 patient-years in 2013 compared with the mean for the other ACOs in its cohort.

Figure 2 shows the number of hospital readmissions for any reason during the first 30 days following discharge, per 1,000 admissions, in Wilmington Health’s MSSP from 2010 through 2013, as well as the mean for the other ACOs in the MSSP cohort at the end of 2013. The readmission rate for Wilmington Health decreased by 13% between 2010 and
2013, and Wilmington Health’s readmission rate in 2013 was 17% lower than the mean rate for the other ACOs in its MSSP cohort.

Figure 3 illustrates how the use of advanced imaging changed as Wilmington Health transformed its practices; specifically, this figure shows the number of computed tomography (CT) scans per 1,000 patient-years performed in Wilmington Health’s MSSP from 2010 through 2013, as well as the mean for the other ACOs in the MSSP cohort at the end of 2013. In 2010, CT use at Wilmington Health was significantly higher than the mean for the other ACOs in the cohort; however, the number of CT scans per 1,000 patient-years in Wilmington Health’s MSSP dropped dramatically in 2011 and continued to decline in 2012 and 2013. The number
of CT scans per 1,000 patient-years was 34% lower in 2013 than in 2010, and Wilmington Health is now outperforming the other ACOs in its cohort on this measure as well.

Wilmington Health has shown year-on-year improvement for the past 4 years in almost every category for which data are reported to CMS. One of the most-reviewed measures is the total cost of care per Medicare beneficiary; on this measure, Wilmington Health has achieved a cost that is 21% lower than the average for the other ACOs in its MSSP cohort.

The challenge of many ACOs across the country is building a sustainable model in the absence of best practices. Because there are few model ACOs from which lessons can be learned, Wilmington Health is taking a very pragmatic approach to the development and deployment of the necessary population health data platforms. Thanks in part to this approach, Wilmington Health has been able to accomplish the results described above through normal operations, having increased its staff by only 3 full-time-equivalent positions.

Wilmington Health has learned 2 important lessons on this journey: First, once physicians trust the information being provided, regardless of the data source, they will do the right thing even in the absence of financial incentives. Second, total transparency of performance data can allow an organization to achieve remarkable results very quickly.

Jeffry G. James, CPA, MBA chief executive officer, Wilmington Health, Wilmington, North Carolina.

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Use of Big Data by Blue Cross and Blue Shield of North Carolina

Susan C. Helm-Murtagh

The health care industry is grappling with the challenges of working with and analyzing large, complex, diverse data sets. Blue Cross and Blue Shield of North Carolina provides several promising examples of how big data can be used to reduce the cost of care, to predict and manage health risks, and to improve clinical outcomes.

The term “big data” refers to data sets characterized by volume, complexity, diversity, and timeliness. Within the health care industry, data volumes have grown significantly over the past several years; a recent estimate placed the total volume of health care data at about 150 exabytes (or 150 billion gigabytes) in 2011, and this volume is expected to increase by 1.2 to 2.4 exabytes every year [1, 2]. To put that number in context, 150 exabytes is roughly equivalent to the total amount of data transferred over the Internet each year.

Health care data are also diverse—including both structured forms (data that resides in a fixed field within a record or a file) and unstructured forms (data such as images and text)—and are generated in numerous places to serve a variety of needs (and are thus poorly standardized). Genomic data are an extreme yet relevant example of both the complexity and the potential of health care data. Finally, some health care data are characterized by a need for timeliness; for example, wearable or implantable biometric sensors can generate data—such as measurements of blood pressure, movement, or heart rate—that must be collected and analyzed in a real-time fashion in order to be useful.

What is driving the use of big data in health care? The short answer is that the demand for and opportunities associated with big data are being accelerated and facilitated by the removal of barriers that had formerly limited its use. Health-related information—in the form of electronic medical records, medical images, monitoring device data, biometric data, and even social media data—is increasingly being digitized. The Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009 (Title XIII of the American Recovery and Reinvestment Act of 2009 [3]) provides incentives for the use of electronic medical records, and the granularity and accuracy of diagnosis data are being improved by regulatory mandates such as the upcoming adoption of the International Classification of Diseases, 10th Revision, Clinical Modification (ICD-10-CM). The pressure to reduce costs and improve outcomes is also generating new models of care and payment, such as accountable care organizations (ACOs) and patient-centered medical homes (PCMHs), which require the integration and analysis of clinical and financial data. Finally, the proliferation of consumer-directed health plans and the advent of both private and public health benefit exchanges mean that more consumers are becoming involved in the process of deciding about and purchasing health care; in short, health care is becoming more like a retail marketplace, thus requiring the collection and analysis of data regarding consumer behavior.

At the same time, technology advances such as cloud computing and the application of machine-learning techniques to health care analytics are reducing the cost, storage, and complexity barriers that had previously limited the processing and analysis of large data sets. Entrepreneurial energy, enabled by unprecedented and accelerating levels of venture capital investment in digital health, is maintaining the fast pace of innovation in this sector—more than $1.5 billion was invested during the first 3 quarters of 2013 alone [4]. In addition, the open-data movement at the federal and state government levels—in combination with the push for interoperability standards such as the Standards and Interoperability Framework of the Office of the National Coordinator for Health Information Technology—signals the potential removal of hurdles that had blocked the way to data standardization and accessibility.

The use of big data in health care presents several well-documented opportunities: improvement of health outcomes through more accurate and precise diagnoses; identification of patients who are at risk of adverse outcomes; closing of gaps in care; customization of care at the level of the individual patient (personalized medicine); improvement of adherence to medication regimens; reduction of costs through earlier detection of disease; elimination of unnecessary and duplicate care; reduction in variations in care; elimination of erroneous, improper, and fraudulent claims submissions;
enhancement of member and patient experiences; and improvement of communication with health plan members and patients to encourage healthier lifestyles.

These opportunities are promising, but there are also major challenges to the use of big data in health care: the need for data privacy and security; the critical importance of data accuracy in a system that relies heavily on manual, error-prone data-entry practices; and the problem of data fragmentation (as shown in Figure 1) [5, 6]. As a result, the health care sector is still in the early stages of adopting and applying big data. Health plans (payers) are just beginning to evolve from using primarily claims data to integrating claims, clinical data, and behavioral data. However, as the following examples show, early efforts by Blue Cross and Blue Shield of North Carolina (BCBSNC) are beginning to demonstrate the actual and potential value of big data.

Improving Quality of Care and Lowering Costs in PCMHs

BCBSNC’s internal examination of utilization and cost trends over a 3-year period for several hundred PCMH practices in North Carolina showed that overall medical expenditures were 4% lower in PCMH practices than in non-PCMH practices. This savings is driven by a 10%-12% reduction in the rate of inpatient admissions, 20% fewer emergency department (ED) visits, and a 10%-15% reduction in visits to primary care provider offices (BCBSNC internal data). These reductions were partially offset by higher utilization of professional services, but the net result was still that PCMH practices delivered higher-quality care for a lower cost. These results are generally consistent with those of published studies of PCMH implementations in other states, although some of the larger savings reported by other studies could reflect differences in the analytic methodology that was used, the size of the sample, or the implementation phase of the PCMH at the time it was evaluated.

Predicting Obesity

BCBSNC has developed a set of predictive models to stratify members’ health risk and inform outreach efforts using claims data supplemented with demographic and behavioral data, such as purchasing preferences, leisure interests, and exercise habits. One output of the model involves the prediction of obesity in the absence of coded claims or specific biometric data. A recently performed statistical validation of the model against actual body mass index (BMI) data obtained via health assessment showed strong predictive performance in a population of 100,000 individuals; the highest-risk individuals identified by the model had an average actual BMI of 38 kg/m². In addition, when all subjects with health assessment data were sorted into demi-decile groups from highest to lowest obesity score, the predicted BMI for each group was within 1.5 kg/m² of the actual BMI (BCBSNC internal data). This predictive model can be used to trigger outreach to members, which could consist of health coaching, nutritional counseling, or other health promotion programs.

Predicting and Managing Other Health Risks

BCBSNC has also developed a risk analysis model that helps to explain how members who have been continuously enrolled for 2 years have progressed along the care continuum as a result of various interventions. Several types of
data—including claims data, behavioral data, and clinical data—are aggregated to formulate a specific risk score for each health plan member. This model calculates the number of members who are healthy, the number who are at risk, the number who have chronic conditions, and the number who have complex medical issues; it then shows how members have moved between those categories over time. These data can be used to identify specific cost drivers for that subpopulation and to help determine which benefit design strategies, network changes, health management programs, or wellness interventions are most likely to help these individuals manage their risks.

**Decreasing Inappropriate ED Utilization**

BCBSNC is also using statistical models to identify individuals who may be likely to use ED services inappropriately. This model uses information about health conditions, prior use of health care resources (eg, having a primary care provider), socioeconomic factors, and proximity to sites of care to identify which individuals are most likely to use the ED for services that could be provided at another site. The highest-risk individuals account for 50% of all ED “frequent fliers” (defined by BCBSNC as those who make 3 or more ED visits per year), and the vast majority of high-risk individuals will have at least 1 ED visit in the next year. These members receive outreach to educate them about care alternatives that are more appropriate, more convenient, and lower in cost.

**Improving Clinical Outcomes for Knee Replacement Surgery**

For one large employer group that was experiencing rapidly rising orthopedic costs, BCBSNC developed a risk model to predict the likelihood that an individual would need knee replacement surgery during the next 12–18 months. This model allows at-risk individuals to be identified and contacted by a nurse case manager, who can provide them with information regarding their condition, an explanation of their benefit coverage, and assistance in selecting high-quality orthopedic surgeons at network facilities with the best clinical outcomes. The nurse case managers can help members understand and predict their specific out-of-pocket costs and can promote BCBSNC’s bundled knee-replacement arrangements.

Although member satisfaction scores, cost savings, and clinical outcomes are still pending, we are confident that giving people accurate data with which to navigate the complex health care system will move us closer to achieving the Institute for Healthcare Improvement’s Triple Aim—improving the patient experience of care, improving the health of populations, and reducing the per-capita costs of health care [7].

**Conclusion**

Opportunities abound for the application of big data in health care; recent technology advances, heightened market interest (and investment), and legislative changes are facilitating and accelerating the realization of those opportunities. BCBSNC is committed to responsibly exploring and leveraging big data to reduce the cost of care, to predict and manage health risks, and to improve clinical outcomes. NCMJ

Susan C. Helm-Murtagh, DrPH vice president, Information Management and Analytic Services, Blue Cross and Blue Shield of North Carolina, Durham, North Carolina; and adjunct assistant professor, Department of Health Policy and Management, UNC Gillings School of Global Public Health, University of North Carolina at Chapel Hill, Chapel Hill, North Carolina.

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Improving Quality of Health Care Using the North Carolina Immunization Registry

Amanda Dayton

The North Carolina Immunization Registry (NCIR) is a secure, Web-based clinical tool that serves as an official record of immunization status. This commentary provides an overview of the NCIR and describes how providers, communities, and public health agencies use its data to improve quality of care.

The North Carolina Immunization Registry (NCIR) began in 1996 as a part of the Health Service Information System, a mainframe computer system accessible only by local health departments. In 1998 the North Carolina Immunization Branch, which is part of the North Carolina Division of Public Health, began the arduous process of moving the NCIR from the mainframe to a Web-based system. The process took years and involved securing funding, finding and contracting with a vendor who could customize and maintain the system, and enhancing a similar immunization registry from Wisconsin to meet North Carolina’s specifications. By 2005 the North Carolina Immunization Branch finally had a secure, Web-based registry; this registry now serves as the official source for North Carolina immunization information and produces an official, legal vaccination record.

This new and improved immunization registry began with much of the data from the older system, including the records of approximately 3.5 million individuals. The NCIR also has a number of important features, chief among them the ability to provide clinical decision support by recommending the appropriate vaccines by age according to state requirements and national standards. The upgraded registry also streamlines the vaccine ordering process and has a variety of reporting features to help users better manage vaccine inventory and identify which clients need immunizations.

Rollout of the NCIR started with local health departments and gradually expanded to include private provider offices that receive vaccines from the federally funded Vaccines for Children (VFC) program, which provides vaccines at no cost to children who otherwise might not be vaccinated because of inability to pay. To date, more than 1,200 health care provider offices use the NCIR (Figure 1), including 100% of the state’s local health departments and more than 90% of the pediatric offices and family physicians who administer VFC vaccines [1]. Health care providers who receive VFC vaccines are required to document administration of those vaccines either in the NCIR or by printing out and completing the Vaccines Administered Log available on the Web site of the North Carolina Immunization Branch [2]. There is no requirement for these providers to document administration of privately purchased vaccines, although many do so (Figure 2). Additionally, there is no state requirement for health care providers (other than pharmacists) who do not participate in the North Carolina Immunization Program to use the NCIR.

Despite a modest beginning, the NCIR has a large amount of immunization information, with more than 83 million doses of vaccine recorded in the registry (Figure 3). The NCIR is a life-span registry and contains more than 7 million clients—about 74% of the state’s total population. Thanks to an interface with North Carolina Vital Records, nearly 100% of the infants and young children in the state have records in the NCIR. Furthermore, 95% of children between 4 months and 5 years of age and 86% of adolescents aged 11-17 years who have a record in the NCIR have at least 2 immunizations documented. About 50% of adults aged 19 years or older have a record in the NCIR, and 43% of those with a record have at least 1 immunization documented [1].

Improving Care Through NCIR Utilization

The vast amount of immunization data available in the NCIR enhances the ability of health care providers, communities, and public health agencies to improve the quality of care for North Carolina’s citizens. One of the greatest benefits is assuring that providers have timely access to complete, accurate, relevant immunization data. Having this information available in a consolidated record enhances patient safety both by preventing overimmunization and by identifying those who are underimmunized and therefore at risk for disease. The NCIR also saves money by ensuring that duplicate vaccines are not administered to individuals...
who are already immunized, and it can decrease the need to treat vaccine-preventable disease by identifying those in need of immunizations and preventing unnecessary prophylaxis of contacts with a vaccination history. Multiple studies [3-5] have shown how the use of an immunization information system (IIS) such as the NCIR can improve health care quality, reduce the prevalence of infectious diseases, and save money.

From a clinical perspective, the data in the NCIR offer additional advantages to immunizers by providing clinical decision support. Health care providers have the ability to document in the registry any medical or religious exemptions, parental refusal, adverse reactions, and contraindications to a vaccine. The registry then recommends the vaccines needed for each client at the time of the visit, based on the client’s age, immunization history, and medical history. These recommendations follow immunization requirements specific to North Carolina, as well as standards set by the Advisory Committee on Immunization Practices of the Centers for Disease Control and Prevention. This clinical decision support ensures that the individual patient is protected from disease by receiving the appropriate vaccine at the appropriate time.

Communities also benefit from the information in the NCIR when data are used to assess immunization coverage and to identify areas of underimmunization. The NCIR can easily calculate coverage rates for any age group for a specific vaccine or combination of vaccines. Reports can determine the coverage rate for an individual provider office or health department, and at the level of the county, zip code, or state. Health departments use these reports to identify areas where vaccination is needed and to focus education and outreach on specifically targeted areas. University researchers have also used NCIR data to study the impact of interventions designed to boost immunization rates, factors associated with vaccine uptake, and the degree of agreement between practice records and the NCIR [6-10].

Many provider offices currently use the NCIR to improve
Data-Driven Population Health: Collaboration Between Macon County Public Health and Community Hospitals

James Bruckner, Becky Barr

In North Carolina, local health departments (LHDs) have traditionally led efforts to develop community health improvement plans [1], but their leadership and advocacy in this role must be strengthened and supported by community partnerships. When it comes to the delivery of core and essential public health services, all North Carolina LHDs have similar missions and responsibilities [2], but they differ in size, scope, competency, and capacity to deliver essential services. To compensate for these differences, rural LHDs are most successful when they partner with a variety of community stakeholders in conducting a community health needs assessment (CHNA) and implementing identified priorities.

Macon County Public Health (MCPH) is a medium-sized rural LHD located in Western North Carolina. Several factors differentiate rural counties from their more urban counterparts. First, small communities have a limited number of community partners with whom the LHD can collaborate. If these partners become disenfranchised, a rural LHD may have no way to replace their input. Second, it is important for directors of rural LHDs to maintain healthy relationships with hospital chief executive officers, because poor relations can have a negative impact on LHD program development. Third, relationships are often more personal in rural communities, with information sometimes spreading quickly via word of mouth rather than through formal communication channels.

Even before passage of the Patient Protection and Affordable Care Act of 2010, LHDs began to notice that the roles of the private and public health sectors were shifting in such a way that future population health efforts would require cooperation and strong partnerships. LHDs have long advocated for and provided most of the population-based health initiatives at the community level, and developing strong partnerships with private-sector health organizations such as hospitals can lead to improvements in quality, reductions in the cost of health services, and ultimately improvements in population health [3].

In Macon County, CNAs were conducted in 2011 and 2012. The 2012 assessment was conducted in an effort to align MCPH with the CHNA schedule of the county’s nonprofit hospitals, which must perform a CHNA and adopt an implementation strategy every 3 years in order to retain their tax-exempt status [4]. In conducting the 2012 CHNA, MCPH partnered with Angel Medical Center in Franklin, Highlands-Cashiers Hospital in Highlands, and specific employees of MedWest Health System in Clyde. The CHNA committee was made up of staff members from all 4 organizations and other key community stakeholders.

The first step in the assessment process involved getting all of the partners to agree on a standardized method for collecting, analyzing, and prioritizing data. The process then required collecting information via a telephone survey, conducting focus group discussions, interviewing key informants, and reviewing the available statistical data. Once the data were collected and analyzed, MCPH and the partnering hospitals identified 3 health priorities: reduction in the incidence of preventable chronic diseases related to obesity; improved access to care through recruitment and retention of additional primary care physicians and dental practitioners; and reduction in the incidence and mortality rates of breast, colon, and lung cancer through prevention and early intervention [5].

To address these priorities, several new evidence-based initiatives have been implemented. Highlands-Cashiers Hospital has collaborated with MCPH to expand a diabetes self-management training program at their facility. MedWest Health System is working with 6 LHDs and Western Carolina University to implement a regional mobile endocrinology clinic. Angel Medical Center has

their immunization rates by producing reminder/recall reports that identify which specific clients need vaccines. The NCIR can generate client-specific reminder letters and mailing labels, and it can also produce data for use in autodialer systems. This functionality helps providers ensure that their patients are fully protected at all times, and it helps ensure they do not miss opportunities for vaccination.

The NCIR has also proved to be an invaluable tool to ensure the public’s safety in the event of public health emergencies, such as natural disasters, disease outbreaks, vaccine recalls, and vaccine shortages. After Hurricane Katrina, North Carolina had access to the Louisiana immunization registry and to the immunization records of children who

were forced to evacuate. In addition, North Carolina has seen a number of vaccine-preventable disease outbreaks in the past few years, including cases of hepatitis A, pertussis, and measles. In each of these instances, registry data were used to ensure that appropriate quantities of vaccine were available to providers in areas affected by disease, and to facilitate the redistribution of vaccine as necessary. The NCIR was also used to assess the immunization status of those in the community who had been exposed and those deemed to be at risk. During vaccine recalls, the NCIR assists in the public health response; for example, during the 2007 recall of vaccine for Haemophilus influenzae type b (Hib), the NCIR determined which providers had already
sponsored diabetes programs at “ladies night out” events and has kicked off a weight-loss program, Lighten Up 4 Life [6]. Angel Medical Center has also required new hospital-based physicians to volunteer time at Community Care Clinic of Franklin and has promoted the American Cancer Society’s Cancer Prevention Study-3, a multiyear survey studying lifestyle, behavioral, environmental, and genetic factors that may cause or prevent cancer [7]. Finally, MCPH has added a second registered dietitian to its diabetes self-management training program and has expanded its gestational diabetes education services.

These new programs have had a significant impact on population health. Five-year diabetes mortality rates fell to 16.8 per 100,000 population in 2008-2012 [8] from 23.0 per 100,000 population in 2003-2007 [9], and 71% of the patients who completed MCPH’s diabetes self-management training program reduced their glycated hemoglobin level to 6.5% or lower (personal communication from registered dietitian Jessi Bassett, January 2014). In addition, participants in the Angel Medical Center’s Lighten Up 4 Life program have collectively lost more than 4,775 pounds [6].

In small rural communities such as Macon County, it is imperative that LHDs form sound partnerships in order to strengthen their capacity to deliver core and essential public health services. Hospital leaders can have a major impact on public health initiatives through their access to resources, including staff and funding. Because of this reality, all partners within a community must fully invest in CHNAs as a way of reaching consensus about the direction and focus of their population health interventions.

References

Opportunities. House Bill 832 [11], which expands the role of immunizing pharmacists by allowing them to administer recommended vaccines to adults, directly increased access to the NCIR. The bill requires immunizing pharmacists to consult the patient’s immunization history and to document administered vaccines in the NCIR. The passage of this bill is expected to add approximately 2,000 new pharmacy organizations to the NCIR. The quantity of adult immunization information in the registry is expected to grow exponentially as a result of this bill.

An additional driving force that is improving access to immunization registries is the Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009 (Title XIII of the American Recovery and Reinvestment Act [12]). This law encourages providers...
with electronic health records (EHRs) to submit electronic immunization data to an IIS in a “meaningful” manner to improve quality of care. In order to receive financial incentives, providers must meet certain criteria, including those related to sharing electronic data with an IIS, at 3 successive stages [13, 14].

Over the past few years, the North Carolina Immunization Branch has secured federal grants to make modifications to the NCIR so that it will be able to interface bidirectionally with EHR systems. This interface will allow providers to access the NCIR directly from their EHRs in order to obtain a client’s immunization history and vaccine recommendations before administering a vaccine and to update the NCIR after the vaccine is administered. Providers will no longer need to maintain immunization information in both systems separately, as they do now. Eliminating this duplicate data-entry has the potential to significantly improve providers’ work flow. In North Carolina, the plan is to facilitate the connection between the NCIR and EHRs through the use of the North Carolina Health Information Exchange and other vendor hubs. These efficiencies and opportunities for improved care—which will benefit providers, communities, and public health departments—are expected to continue as access to the NCIR increases.

**Challenges.** The NCIR interface supports interoperable functionality above what the Centers for Medicare & Medicaid Services require for practices to meet stage 1 or stage 2 meaningful use criteria. Providers who are trying to meet stage 1 meaningful use criteria must submit a test file. Those who are trying to meet stage 2 meaningful use criteria are required to send updated transactions to the NCIR on an ongoing basis. It is not until they are trying to meet stage 3 meaningful use criteria that EHR systems will need the capacity to query and receive a response from the IIS [13].

This presents a challenge for all users of the NCIR, because the value of the registry lies in its clinical support capabilities. If providers only update client information in the NCIR, without first querying the registry to get a complete picture of the patient’s history (including contraindications and adverse reactions), then the clinical benefits of having such a system are reduced. In addition, providers cannot rely exclusively on the clinical decision support services found in their EHR system, because studies have shown that those services are limited compared with what is found in immunization registries [14]. There is currently wide variation among EHRs in their capacity to support bidirectional interoperability. This capability is crucial in order to optimize the NCIR’s clinical decision support features.

An additional challenge for VFC providers, because of the potential impact on vaccine ordering, is that a high level of accuracy is required for the data being transmitted through their EHR systems to the NCIR. If there is a large discrepancy between inventory in the NCIR and the doses administered as reported by the EHR system, it could affect the amount of VFC vaccine that the provider is able to order.

**FIGURE 3.**
Number of Client Records and Number of Documented Immunizations in the North Carolina Immunization Registry, 2005–2013
Conclusion

The NCIR has been a widely accepted, valuable asset to immunization providers across the state for a number of years. The quality and accuracy of the data within the registry make it a useful tool that health care providers, communities, and public health agencies can use to improve the quality of care provided to North Carolina’s citizens. With improved access to the NCIR, the benefits that make it so valued—such as its clinical decision support and timely access to complete, accurate, relevant immunization data—will be available to more health care providers, which will further patient safety and saving of both time and money. However, this increased access presents a unique challenge, in that a high standard of data accuracy is necessary for the registry to remain clinically beneficial for all.


Acknowledgments

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References

The current clinical research system does not produce high-quality evidence quickly enough to support health care decision making. The Patient-Centered Outcomes Research Network (PCORnet) embodies a novel strategy for creating a national “network of networks” that is capable of significantly accelerating evidence generation to support a learning health system.

The Patient-Centered Outcomes Research Network (PCORnet) represents the confluence of several evolving concepts in clinical care and biomedical research. First among these is the view that patients should be involved in the prioritization, design, conduct, analysis, interpretation, and dissemination of research. Second is the belief that patients, caregivers, health care providers, and systems will be able to make better decisions about health and health care if they have access to high-quality, relevant comparative data about therapies and treatment strategies. Third, as our understanding of the need for evidence to support clinical decision making has evolved, the Institute of Medicine of the National Academies and others have championed the concept of the learning health system, in which research and care are integrated to drive a cycle of continuous learning and improvement.

PCORnet also represents a response to widespread frustration with the current clinical research system, which is producing reliable evidence at only a fraction of the rate needed to meaningfully inform the decisions of system stakeholders. For example, a study of cardiovascular practice guidelines found that most (about 88%) of the clinical recommendations included in these guidelines were not based on high-quality evidence. Furthermore, the limitations imposed by the costs and inefficiencies of clinical trials were acknowledged more than a decade ago, and numerous entities have since attempted to address these problems.

In 2002 the National Institutes of Health (NIH) convened stakeholders to discuss problems facing medical research, and the NIH Roadmap for Medical Research was launched in 2004. This roadmap included a call for the construction of a national system that would allow research activities to be conducted in the context of clinical care with the full participation of patients, their families, and care providers (see Table 1); this system would use electronic health records (EHRs) as its major source of data. The NIH projected that such a plan would take more than a decade to create and implement and concluded that it could not support the full cost of such a network. The NIH ultimately decided to fund the Clinical and Translational Science Award (CTSA) program to provide infrastructure and training for clinical and translational research, but it specifically decided not to fund a national clinical research network. PCORnet, which is funded by a nongovernmental organization (the Patient-Centered Outcomes Research Institute), works in concert with the CTSA infrastructure and training system and has specific alliances with multiple components of the NIH.

These programs have been complemented by other efforts such as the Clinical Trials Transformation Initiative (CTTI). CTTI is a nonprofit public-private partnership that includes representatives from the US Food and Drug Administration (FDA) and more than 60 academic, industry, volunteer, and government organizations. CTTI’s efforts are predicated on the belief that incremental improvements in the clinical research system are insufficient to meet stakeholder needs and that transformational change is therefore required.

Amid this ferment, PCORI, which is an independent, congressionally authorized institute, articulated a vision for a new type of national network for comparative effectiveness research—PCORnet. In 2013 PCORI released a request for proposals for a coordinating center and announced a funding opportunity for multiple networks to form a national “network of networks” that could provide the needed transformational change. PCORnet is not intended...
to replace randomized clinical trials; instead, it represents a complementary effort that is designed to engage multiple stakeholders and to allow a diverse array of otherwise impracticable designs to be implemented. Ultimately, PCORnet may allow us to conduct more cost-efficient clinical trials, thus answering research questions more rapidly and at a lower cost.

The Network

The structure of PCORnet is depicted in Figure 1. The primary entities are 11 clinical data research networks (CDRNs) and 18 patient-powered research networks (PPRNs). These networks are served by the PCORnet Coordinating Center, which is led by the Harvard Pilgrim Health Care Institute and the Duke Clinical Research Institute. The entire consortium is further organized into 11 task forces that will develop the network’s standards and operating principles. Our goal is to achieve significant functionality by September 2016.

**CDRNs.** The CDRNs encompass much of the United States (Table 2). Each network represents a unique partnership of 2 or more health systems and must have full access to the EHRs of at least 1 million patients. Some networks include whole cities (eg, New York and Chicago), while others are state consortia (the Greater Plains Collaborative network, which involves 7 states), large university consortia (the campuses of the University of California form one network, and there is a mid-Atlantic consortium consisting of the University of Pittsburgh, Johns Hopkins University, Penn

### TABLE 1. A Plan for Reengineering the Clinical Research Enterprise: The National Institutes of Health (NIH) Roadmap

<table>
<thead>
<tr>
<th>Goals for years 1-3</th>
<th>Goals for years 4-7</th>
<th>Goals for years 8-10</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Lowest level of difficulty</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Plan and start a few demonstration clinical research networks.</td>
<td>• Create a funding mechanism to sustain a national system through consensus of all constituents.</td>
<td>• A national clinical research system will be in place that creates data on effectiveness, outcomes, and quality of care and moves those data into the community rapidly.</td>
</tr>
<tr>
<td>• Carry out demonstration projects to show how complex regulatory systems might be simplified.</td>
<td>• Put in place a simplified regulatory system for clinical research networks.</td>
<td>• A sustained efficient infrastructure will be in place that can rapidly initiate large clinical trials.</td>
</tr>
<tr>
<td>• Put a plan in place for clinical research networks for all NIH institutes.</td>
<td></td>
<td>• Scientific information will be made available to patients, families, and advocacy groups.</td>
</tr>
</tbody>
</table>

| **Intermediate level of difficulty** |
| • Establish repositories of biological specimens and standards for collection. | • Data standards will be shared across all NIH institutes. | • NIH, CMS, FDA, DOD, and CDC will have agreed on a single medical nomenclature with national data standards. |
| • Standardize nomenclature, data standards, core data, and forms for most major diseases. | • Funding mechanisms will be evaluated to determine which are most efficient. | • Data standards will be updated in real time through networks. |
| • Start a library of these elements shared between the institutes and NLM. | | • There will be a national repository of images and samples. |
| • Develop efficient network administration infrastructure at the NIH. | | • There will be a list of critical national problems. |
| • Develop standards for capturing images for research. | | • The most efficient network funding mechanisms will be in place across the NIH. |

| **Highest level of difficulty** |
| • Create NIH standards that provide a “safe haven” for clinical research. | • NIH standards that provide a safe haven will be in place. | • Participation in research will be a professional standard taught in all health professions schools. |
| • Inventory and evaluate existing public-private partnerships, networks, clinical research institutions, and regulatory systems. | • FDA and CMS regulations and ethics will be harmonized. | • Study of, evaluation of, and training in clinical research will be a part of the curriculum of every medical school, nursing school, and school of pharmacy. |
| • Establish forums of all stakeholders. | • Mechanisms for public-private partnerships will be in place. | • Clinical research practices will be documented and updated regularly to maintain a safe haven. |
| • Establish standards for and pilot the creation of a National Clinical Research Corps. | • The National Clinical Research Corps will have 100,000 members. | • Clinical research networks will provide detailed training about network-specific issues. |
| • Offer demonstration and planning grants to those wanting to enhance, evaluate, or develop model networks. | • Standards will be shared across the NIH. | |

State College of Medicine, and Temple University School of Medicine), a consortium of 8 children’s hospitals (led by the Children’s Hospital of Philadelphia), and a consortium with a single university (Vanderbilt University) tied to an extensive regional network. These CDRNs will provide capacity for amassing data on common diseases in very large populations, as well as data on rare diseases in cohorts that are smaller but still sufficiently large to conduct meaningful clinical trials and observational studies.

PPRNs. In contrast to CDRNs, PPRNs are led by patients and patient advocates who have an intense interest in a specific disease; half of the PPRNs focus on rare diseases and half focus on common diseases (Table 3). Some offer extensive and well-characterized registries and biobanks, whereas others are marked by groups of enthusiastic, active patients who may be relatively inexperienced with regard to data collection and analysis but who share a deep commitment to advancing knowledge through clinical research.

The Coordinating Center. The PCORnet Coordinating Center provides technical and logistical support and works closely with PCORI to guide the consortium toward milestones that will allow the network to produce reliable research results at a fraction of current costs. The Coordinating Center is a virtual entity led by the Harvard Pilgrim Health Care Institute and the Duke Clinical Research Institute; it also has significant hubs at the Brookings Institution (focused on policy), AcademyHealth (focused on support for methods), Johns Hopkins University (focused on ethics), and America’s Health Insurance Plans.

The steering committee. The steering committee includes representatives from patient advocacy groups, industry, and multiple government agencies, including the FDA, the NIH, the Centers for Medicare & Medicaid Services, and the Office of the National Coordinator for Health Information Technology. All PCORnet proceedings are public, and an explicit goal of the project is to enable nonfunded groups to work with the network in conducting both interventional clinical trials and observational studies.
### Patient-Centered Outcomes Research Network (PCORnet) Clinical Data Research Networks (CDRNs)

<table>
<thead>
<tr>
<th>Network</th>
<th>Organization(s)</th>
<th>Principal investigator</th>
<th>Clinical conditions of interest</th>
<th>High prevalence</th>
<th>Rare</th>
<th>Populations covered</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accelerating Data Value Across a National Community Health Center Network (ADVANCE)</td>
<td>Oregon Community Health Information Network</td>
<td>Jennifer DeVoe, DPhil, MD</td>
<td>Diabetes mellitus, HIV/hepatitis C coinfection</td>
<td>Underserved, rural, urban, rare disorders, children, minority, other vulnerable populations</td>
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<tr>
<td>Chicago Area Patient Centered Outcomes Research Network (CAPriCORN)</td>
<td>Chicago Community Trust</td>
<td>Terry Mazany, MA, MBA</td>
<td>Anemia, asthma, Sickle cell disease; recurrent Clostridium difficile colitis</td>
<td>Underserved, rural, urban, rare disorders, children, geriatric, minority</td>
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<td>Greater Plains Collaborative (GPC)</td>
<td>University of Kansas Medical Center</td>
<td>Lemuel Waitman, PhD</td>
<td>Breast cancer, Amyotrophic lateral sclerosis</td>
<td>Underserved, rural, urban, rare disorders, children, geriatric, minority, disabled, other vulnerable populations</td>
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<tr>
<td>Kaiser Permanente and Strategic Partners Patient Outcomes Research To Advance Learning (PORTAL) Network</td>
<td>Kaiser Foundation Research Institute</td>
<td>Elizabeth A. McGlynn, PhD</td>
<td>Colorectal cancer, Severe congenital heart disease</td>
<td>Underserved, rural, urban, rare disorders, children, geriatric, minority, disabled, other vulnerable populations</td>
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<tr>
<td>Louisiana CDRN (LACDRN)</td>
<td>Louisiana Public Health Institute</td>
<td>Anjum Khurshid, PhD, MPAff, MBBS</td>
<td>Diabetes mellitus, Sickle cell disease; rare cancers</td>
<td>Underserved, rural, urban, rare disorders, children, geriatric, minority, disabled, other vulnerable populations</td>
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<tr>
<td>Mid-South CDRN</td>
<td>Vanderbilt University</td>
<td>Russell Rothman, MD, MPH</td>
<td>Coronary heart disease, Sickle cell disease</td>
<td>Underserved, rural, urban, rare disorders, children, geriatric, minority, disabled, other vulnerable populations</td>
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<tr>
<td>National Pediatric Learning Health System (PEDSnet) of Philadelphia</td>
<td>Children's Hospital of Philadelphia</td>
<td>Christopher B. Forrest, MD, PhD</td>
<td>Inflammatory bowel disease, Hypoplastic left heart syndrome</td>
<td>Underserved, urban, rare disorders, children, minority</td>
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<td>New York City Clinical Data Research Network (NYC-CDRN)</td>
<td>Weill Medical College of Cornell University</td>
<td>Rainu Kaushal, MD, MPH</td>
<td>Diabetes mellitus, Cystic fibrosis</td>
<td>Underserved, urban, rare disorders, children, geriatric, minority, disabled, other vulnerable populations</td>
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<tr>
<td>Patient-oriented SCAlable National Network for Effectiveness Research (pSCANNER)</td>
<td>University of California, San Diego</td>
<td>Lucila Ohno-Machado, MD, MBA, PhD</td>
<td>Congestive heart failure, Kawasaki disease</td>
<td>Underserved, urban, rare disorders, children, geriatric, minority, disabled</td>
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<td>PaTH: Towards a Learning Health System in the Mid-Atlantic Region (formerly P2aTH)</td>
<td>University of Pittsburgh</td>
<td>Rachel Hess, MD, MS</td>
<td>Atrial fibrillation, Idiopathic pulmonary fibrosis</td>
<td>Underserved, rural, urban, rare disorders, children, geriatric, minority, other vulnerable populations</td>
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<td>Scalable Collaborative Infrastructure for a Learning Healthcare System (SCILHS)</td>
<td>Harvard University</td>
<td>Kenneth Mandl, MD, MPH</td>
<td>Osteoarthritis, Pulmonary arterial hypertension</td>
<td>Underserved, rural, urban, rare disorders, children, geriatric, minority, disabled, other vulnerable populations</td>
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</table>


**PCORnet task forces.** The PCORnet task forces provide a venue for coordinating efforts across CDRNs and PPRNs. Each task force includes both patients and professional experts who are representatives from the constituent networks. Together, CDRNs, PPRNs, and task forces constitute a national “research fabric” that includes patients as decision makers on questions of priorities, design, conduct, and dissemination.

**Major Challenges**

The overall goal of PCORnet is to conduct clinical research more quickly, to improve reliability and quality, and to significantly reduce costs. However, such an ambitious project comes with a number of potential impediments, and several central challenges have been identified, including extraction and harmonization of data extracted from multiple different EHRs, creation of a common data model, ethical and regulatory issues posed by cluster-randomized designs and comparative effectiveness studies, and methods for engaging patients and consumers. The task forces are working hard to address these challenges, but due to the short timeline for development of the network, some choices about how to organize a clinical research network must be made in the absence of empirical proof of best
<table>
<thead>
<tr>
<th>Network</th>
<th>Organization</th>
<th>Principal investigator</th>
<th>Condition(s)</th>
<th>Proposed population</th>
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<td><strong>Non–rare disease PPRNs</strong></td>
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<tr>
<td>Multiple Sclerosis Patient-Powered Research Network</td>
<td>Accelerated Cure Project for Multiple Sclerosis</td>
<td>Robert McBurney, BSc, PhD</td>
<td>Multiple sclerosis</td>
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<td>Sleep Apnea-Patient Centered Outcomes Network (SA-PCON)</td>
<td>American Sleep Apnea Association</td>
<td>Susan Redline, MD, MPH</td>
<td>Sleep apnea</td>
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<td>ImproveCareNow: A Learning Health System for Children with Crohn’s Disease and Ulcerative Colitis</td>
<td>Cincinnati Children’s Hospital Medical Center</td>
<td>Peter Margolis, MD, PhD</td>
<td>Pediatric Crohn disease and ulcerative colitis</td>
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<td>COPD Patient Powered Research Network</td>
<td>COPD Foundation</td>
<td>Richard Mularski, MD, MS</td>
<td>Chronic obstructive pulmonary disease</td>
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<td>CCFA Partners Patient Powered Research Network</td>
<td>Crohn’s and Colitis Foundation of America</td>
<td>R. Balfour Sartor, MD</td>
<td>Inflammatory bowel disease (Crohn disease and ulcerative colitis)</td>
<td>30,000</td>
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<td>ARthritis patient Partnership with comparative Effectiveness Researchers (AR-PoWER PPRN)</td>
<td>Global Health Living Foundation</td>
<td>Seth Ginsberg, BS</td>
<td>Arthritis (rheumatoid arthritis, spondyloarthritis), musculoskeletal disorders (osteoarthritis), and inflammatory conditions (psoriasis)</td>
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<td>Mood Patient-Powered Research Network</td>
<td>Massachusetts General Hospital</td>
<td>Andrew Nierenberg, MD</td>
<td>Major depressive disorder and bipolar disorder</td>
<td>50,000</td>
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<tr>
<td>Health eHeart Alliance</td>
<td>University of California, San Francisco</td>
<td>Mark Pletcher, MD, MPH</td>
<td>Cardiovascular health</td>
<td>100,000</td>
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<tr>
<td>American BRCA Outcomes and Utilization of Testing Patient-Powered Research Network (ABOUT Network)</td>
<td>University of South Florida</td>
<td>Rebecca Sutphen, MD</td>
<td>Hereditary breast and ovarian cancer</td>
<td>17,000</td>
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<tr>
<td><strong>Rare disease PPRNs</strong></td>
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<td>ALD Connect</td>
<td>ALD Connect, Inc.</td>
<td>Florian Eichler, MD</td>
<td>Adrenoleukodystrophy</td>
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<td>NephCure Kidney Network for Patients with Nephrotic Syndrome</td>
<td>Arbor Research Collaborative for Health</td>
<td>Bruce Robinson, MD, MS</td>
<td>Primary nephrotic syndrome (focal segmental glomerulosclerosis, minimal change disease, and membranous nephropathy), multiple sclerosis</td>
<td>1,250</td>
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<td>Patients, Advocates and Rheumatology Teams Network for Research and Service (PARTNERS) Consortium</td>
<td>Duke University</td>
<td>Laura Schanberg, MD</td>
<td>Juvenile rheumatic disease</td>
<td>9,000</td>
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<td>Rare Epilepsy Network (REN)</td>
<td>Epilepsy Foundation</td>
<td>Janice Buelow, PhD, RN</td>
<td>Aicardi syndrome, Lennox-Gastaut syndrome, Phelan-McDermid syndrome, hypothalamic hamartoma, Dravet syndrome, tuberous sclerosis</td>
<td>1,500</td>
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<tr>
<td>Community-Engaged Network for All (CENA)</td>
<td>Genetic Alliance, Inc.</td>
<td>Sharon Terry, MA</td>
<td>Alström syndrome, dyskeratosis congenital, Gaucher disease, hepatitis, inflammatory breast cancer, Joubert syndrome, Klinefelter syndrome and associated conditions, metachromatotic leukodystrophy, pseudoxanthoma elasticum, psoriasis</td>
<td>50–50,000</td>
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<td>PI Patient Research Connection: PI-CONNECT</td>
<td>Immune Deficiency Foundation</td>
<td>Kathleen Sullivan, MD, PhD</td>
<td>Primary immunodeficiency diseases</td>
<td>1,250</td>
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<td>DuchenneConnect Patient-Report Registry Infrastructure Project</td>
<td>Parent Project Muscular Dystrophy</td>
<td>Holly Peay, MS</td>
<td>Duchenne and Becker muscular dystrophy</td>
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<td>Phelan-McDermid Syndrome Data Network</td>
<td>Phelan-McDermid Syndrome Foundation</td>
<td>Megan O’Boyle, BA</td>
<td>Phelan-McDermid syndrome</td>
<td>737</td>
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<td>Vasculitis Patient Powered Research Network</td>
<td>University of Pennsylvania</td>
<td>Peter Merkel, ME, MPH</td>
<td>Vasculitis</td>
<td>500</td>
</tr>
</tbody>
</table>

Note: Full descriptions of PPRNs are available on the PCORnet Web site: http://www.pcornet.org/patient-powered-research-networks/.
practices. For example, should a central institutional review board (IRB) be used, or should IRB reciprocity be required or encouraged? In most cases, a range of options will be available, although in some key areas a PCORnet-wide standard approach will be needed to construct a functional national network.

**Data interoperability.** Despite the promise of EHRs, considerable work remains before interoperable data will be available across PCORnet. A specific approach has been developed that will use the software application PopMedNet to produce data tables for each network, based on common data element definitions and models. These data tables will include basic information about demographic characteristics, diagnoses, medications, procedures, and events. This approach constitutes a substantial challenge, given the documented variability in EHRs both within and among health systems; however, we have reason for confidence thanks to the Mini-Sentinel project (a pilot program for the Sentinel Initiative) [9, 10], which used a distributed data network to amass tens of millions of records (mostly from payers) to conduct massive postmarketing surveillance. Indeed, the integration of comprehensive follow-up data from insurance claims (almost all health care transactions are recorded for the duration of coverage) and deep patient data from integrated health systems—comprising comprehensive information about demographic characteristics, diagnoses, symptoms, laboratory data, imaging, prescriptions, procedures, and clinical and patient-reported outcomes—would provide a comprehensive platform for both observational and interventional research.

**Disruptions to the current system.** Even after data are successfully aggregated, many of the most important questions in the realm of comparative effectiveness research will require active intervention and will often include an element of randomization. At the same time, health system administrators and clinicians continue to express concerns about unsustainable workloads and mounting demands for efficiency in health care delivery. In an increasing number of clinical research projects, the selection of priorities and research design have been consonant with health system goals, which can yield impressive efficiencies in research conduct [11]. Unfortunately, research regarding many important questions will inevitably be disruptive to health systems, and a number of research procedures—including consent—are seen as intrusive, expensive, and burdensome to the clinical care system. Therefore a key component of the PCORnet effort is fostering a sense of community around the shared understanding that continuous learning is a fundamental obligation of health systems, clinicians, and health system administrators.

Emerging issues related to research permissions and oversight present additional problems that must be addressed. The division between practice and research, which is currently being eroded by learning health system concepts, calls into question traditional views of regulation based on the ethical principles enunciated in 1979 in the Belmont Report of the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research [12]. However, well-documented delays in the initiation of clinical research can be ameliorated only by introducing new approaches on a broad scale. Such approaches include enhancement of the role for centralized or shared review of protocols by institutional review boards, the use of modified and simplified consent, and the implementation of oversight structures that are based on levels of risk rather than artificial distinctions between quality improvement and research.

**Adapting to patient-centered research.** The incorporation of patients into every phase of research is a new and evolving concept. In some patient communities—such as patients with HIV/AIDS, breast cancer, cystic fibrosis, or multiple myeloma—patients and their advocates are driving research agendas in full partnership with investigators [14]. Many other communities are just beginning to coalesce, and PPRNs are meant to provide a venue for the development of best practices for patient involvement.

**Communication.** Finally, communication is a major issue for PCORnet and its constituents. Central to the PCORnet effort is the widespread adoption of a common cause and the broad sharing of best practices across its 29 networks, thousands of investigators, and millions of patients. Reconfiguring the clinical research system will require the creation of multimedia materials, user-friendly Web portals, thoughtful approaches to social media, and systems of human contact that create efficiencies across a system that until now has been disorganized and siloed. Significant efforts will be applied to the creation of a publicly available, Web-based “living textbook” designed to harness and combine creative input from thousands of interested people, while at the same time providing high-quality, curated content on multiple aspects of pragmatic clinical research.

**Clinical Trials and Observational Studies**

The success of PCORnet will provide an unprecedented platform for both observational studies and clinical trials. The massive size and distributed design of PCORnet should make it possible to improve the quality of published observational studies. Methods can be considered and refined by a national “brain trust” to control as best as possible for the many issues that often cause observational studies to have irreproducible results. When an interesting result is observed, it should be possible to rapidly attempt to replicate that finding in a different network.

The Clinical Trials Task Force will scrutinize every step in the clinical trial system to design an approach that can meet the demands for dramatically increased evidence generation and substantially reduced costs. Examples include the ability to prioritize research ideas through massive crowdsourcing efforts, which will ensure that the problems being addressed are of keen interest to patients who will volunteer for studies. Equally important is being able to leverage
mature, interoperable EHR systems and foster the capacity
to simulate trial results, find patients, automate baseline
data and outcome collection, and follow patients across
networks.

Conclusion

PCORnet is meant to be a transformative new national
platform for conducting patient-centered comparative
effectiveness research. Our hope is that by involving all con-
stituents in the formulation and construction of the network
over the next 18 months, we will be able to create a network
that the NIH, industry, and PCORI itself can use to increase
the production of reliable evidence that can support deci-
sions about health and health care delivery—potentially by
at least an order of magnitude. NCMJ

Robert M. Califf, MD co–principal investigator of the PCORnet
Coordinating Center, vice chancellor of clinical and translational
research, director of the Duke Translational Medicine Institute, and pro-
fessor, Duke University School of Medicine, Durham, North Carolina.

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All-payer claims databases are being developed in states across the nation to fill gaps in information about the health care system. The value of such databases is becoming more apparent as these databases mature and are used more frequently to help states better understand their health care utilization and costs.

Current developments in health care reform, including the passage and implementation of the Patient Protection and Affordable Care Act of 2010, have prompted health policy professionals and decision makers to call for improved assessment of health care outcomes (such as price transparency, quality, and effectiveness). The need for data-driven evaluation and greater consumer engagement, which is only possible through improved transparency, has been further reaffirmed by the development of accountable care organizations and by the provision of Cycle III funding from the Centers for Medicare & Medicaid Services (CMS) for rate review and development of state data centers. In a number of states, the establishment of all-payer claims databases (APCDs) have filled critical information gaps for state agencies, supported health care and payment reform initiatives, and increased transparency in health care at the state level. States with APCDs are responding to a need for comprehensive, multipayer data that the state and other stakeholders can use to obtain a clearer picture of the cost, quality, and utilization of health care.

Overview of APCDs

APCDs are large-scale databases that systematically collect health care claims data from a variety of payer sources. Statewide APCDs are usually created by a state mandate; in states without a legislative mandate, data may be reported to the APCD voluntarily. APCDs generally include data derived from medical claims, pharmacy claims, eligibility files, provider (physician and health care facilities) files, and dental claims. Payer sources are both public and private and currently include insurance carriers, third-party administrators, pharmacy benefit managers, dental benefit administrators, state Medicaid agencies, and CMS. APCDs may eventually grow to include the Federal Employees Health Benefits program, TRICARE (the program that provides civilian health benefits for military personnel, military retirees, and their dependents), and the Veterans Health Administration.

APCDs collect data from existing claims transaction systems used by payers and health care providers (facilities and practitioners). The information typically collected in an APCD includes patient demographic characteristics; provider demographic characteristics; and clinical, financial, and utilization data. Certain types of information are sometimes omitted because they are difficult to collect; for example, most states implementing APCDs have decided not to include denied claims, workers compensation claims, and data about services provided to uninsured individuals (for which no claims exist) [1]. Despite these exclusions, APCDs can provide an almost-complete sample of a state’s insured population, which makes it possible for these systems to support a broad range of information needs and studies. As Figure 1 shows, 14 states already have APCD systems (3 of which are voluntary rather than state-mandated), and 26 additional states are in various stages of developing an APCD system, ranging from general research by stakeholders to rule making to vendor acquisition. In other states, such as North Carolina, there have been informal meetings and queries regarding the feasibility of APCD reporting, but these have yet to coalesce into legislation or other organized action.

The APCD Council is a learning collaborative of government, private, nonprofit, and academic organizations that focuses on improving the development and deployment of state-based APCDs. This council is convened and coordinated by the Institute for Health Policy and Practice at the University of New Hampshire and by the National Association of Health Data Organizations. The APCD Council has been providing shared learning and technical assistance to states since 2007.

The Value of APCDs

To identify opportunities to improve the public’s health, state governments and health services researchers need high-quality, consistently collected data about population
health across many areas, including health status, health care utilization, access to care, health care quality, and health care costs. Types of data commonly used for health services research include population-based data (eg, hospital discharge data and Medicare claims data) and sample-based data (eg, data from the Medical Expenditure Panel Survey). Although both types of data help to answer very important questions related to health services research, each has certain limitations.

Hospital discharge data are used broadly and in many different ways; for example, such data can be used to study patterns of care in the inpatient setting, to understand rates of hospitalization for disease and injury, and to explore patient characteristics of different hospitals. In addition, the widespread availability of inpatient data has allowed the Agency for Healthcare Research and Quality to develop quality indicators for inpatient care, which serve as standard measures that can be used consistently at the national and state levels [2]. Similar data and quality indicators for office-based care are not publicly available on a population level; however, the majority of health care in the United States is provided in outpatient settings.

CMS collects data based on claims paid by Medicare, including claims for ambulatory care, and it makes these data available for research. Although these data can provide a robust understanding of patterns of care [3], the data are limited to people covered by Medicare—those 65 years of age or older and/or those with permanent disabilities or certain medical conditions. State-based Medicaid program data also provide a wealth of information about the type, quality, and cost of care for the Medicaid population; like Medicare data, however, Medicaid claims reflect care for only a small, albeit important, portion of the population.

Although health services researchers have options for obtaining data about the Medicare and Medicaid populations, data about ambulatory care for the majority of the US population is not available in all states. Sample-based surveys such as the Medical Expenditure Panel Survey provide important data that can be used to analyze care at the national level and in some states, but the sample sizes for these surveys preclude many state and substate analyses and may not allow for analyses of subpopulations (such as those with chronic conditions or disabilities). In many states, population-based data are needed to study priority populations—such as minorities, children, persons with disabilities, and those living in rural areas—because samples rarely include data on enough individuals to allow for analyses in these subpopulations. Recognizing the need for these data, states began developing APCDs because of their potential to provide a much deeper understanding of patterns, quality, and cost of care across the entire population.

Examples of How States Are Using APCDs

In an effort to highlight how states are using their APCDs, the APCD Council in 2013 launched the APCD Showcase (http://www.apcdshowcase.org). This Web site provides...
case studies of how APCDs are being used in several states including Colorado, Maine, Massachusetts, New Hampshire, Utah, and Vermont. Examples from some of these states are provided below.

Colorado has developed a Web site (https://www.cohealthdata.org/#/home) that uses its APCD data to report on health care costs and utilization of services by geographical location (county or zip code). The following types of reports are available: total cost of care per person; total actual cost of care compared with expected cost of care (an average based on the type of people who live in that area); the percentage of all prescriptions filled that are for generic rather than name-brand drugs; rate of hospital readmission for any reason within 30 days of discharge (per thousand population per year); rate of emergency department visits (per thousand population per year); the percentage of individuals with claims indicating a diagnosis of diabetes; the percentage of individuals with claims indicating a diagnosis of asthma; and illness burden, which is a measure of relative health based on the number and type of health services used.

Another example is Vermont’s APCD, the Vermont Healthcare Claims Uniform Reporting and Evaluation System, which was used in combination with other provider data sources to develop primary care service areas for a spatial analysis study of Vermont. A report on the development of these primary care service areas is available at http://gmcboard.vermont.gov/sites/gmcboard/files/PCSA-Spatial-Analysis.pdf.

The Maine HealthCost Web site (http://gateway.maine.gov/MHDO/healthcost/) provides information for consumers and employers about charges and payments for medical care in Maine, organized by insurance plan and by procedure. It also provides the estimated price of medical care for uninsured individuals. Price information is based on APCD data collected by the Maine Health Data Organization.

The Massachusetts Health Connector, the state’s health insurance exchange, applied for and received federal certification to implement a state-based risk-adjustment program. As part of this work, the Massachusetts Health Connector partnered with the administrator of the state’s APCD to leverage this system for data collection. More information about the Massachusetts APCD is available on the Web site of the state’s Center for Health Information and Analysis (www.mass.gov/chia/apcd).

A final example of APCD use is New Hampshire, which used funding from the Assessment Initiative of the Centers for Disease Control and Prevention to launch a Web-based claims data module (http://nhhealthwrqs.org/) to support community health assessment. This module is part of the existing New Hampshire Health Web Reporting and Query System, which allows users to access standard indicators of population health from modules based on vital records data (births and deaths), hospital discharge data (inpatient and emergency department care), cancer registry data, behavioral health data (from the Behavioral Risk Factor Surveillance System and Youth Risk Behavior Surveillance System surveys), and environmental health data from the New Hampshire Environmental Public Health Tracking Program. The claims module was specifically built to allow users to select indicators that include rates of diseases of particular importance for public health, as well as indicators of care for those diseases.

Vision for the Future

Although the core components of APCD development and maintenance remain consistent, the process of developing relationships with stakeholders and implementing APCD systems is constantly evolving and is somewhat unique to each state. As a result, the issues that take priority in APCD development and maintenance will vary by state. Some priority issues identified by states include provider identification, rate review enhancement, standardization of data collection, and the use of APCDs for risk adjustment. These areas of potential enhancement and expansion will play an important role in the future of APCDs.

The value of APCDs to states and their stakeholders is becoming increasingly apparent as more states develop APCDs and existing systems continue to mature. In order to move forward and better assess APCDs and the value that they provide, emphasis should be placed on the need for states to define the uses of APCDs and to provide evidence that APCDs support transparency in health care.

Ashley Peters, MPH project director, Institute for Health Policy and Practice, University of New Hampshire, Durham, New Hampshire.

Jane Sachs, MPH, MBE former project and membership manager, National Association of Health Data Organizations, Salt Lake City, Utah.

Jo Porter, MPH deputy director, Institute for Health Policy and Practice, University of New Hampshire, Durham, New Hampshire.

Denise Love, BSN, MBA executive director, National Association of Health Data Organizations, Salt Lake City, Utah.

Amy Costello, MPH project director, Institute for Health Policy and Practice, University of New Hampshire, Durham, New Hampshire.

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The advent and expansion of electronic medical record systems and open-access databases are creating a “data tsunami.” As this wave descends, we must anticipate and address several ethical and social risks: threats to patient privacy, threats to the reputations of various social groups, and threats to public trust in biomedical research.

TMI—“Too Much Information”—has entered the popular American vernacular as an exclamation of alarm when someone burdens you by disclosing information you would rather not know. It is a common response when a conversation turns suddenly too personal, but it could just as easily apply to the tsunami of biomedical data now looming over us. From one direction, electronic medical record systems are enabling the accumulation of clinical data about large numbers of patients, which is being used to develop evidence-based practice standards and to improve quality of care [1]. From another direction, tools such as genomic sequencing have the potential to make staggering amounts of biological information about patients and their families available for personalized health care [2]. At the convergence of these waves, clinicians and patients are hoping to harness the power of this information to achieve their health and healing goals. As exciting as this prospect may be, however, there will also be dangers and challenges. This commentary highlights 3 ethical and social risks that will be important to anticipate as the wave of biomedical data descends: threats to the health information privacy of individual patients; threats to the reputational identities of the social groups to which patients belong; and threats to the ethical commitment to voluntary participation that has thus far sustained public trust in biomedical research.

Privacy Risks

Keeping patient information confidential was a professional obligation of physicians long before modern notions of personal privacy emerged. Even the Hippocratic healers of ancient Greece understood the role of discretion in building the trust required to address patients’ health problems [3]. In modern times, this fiduciary obligation has been strengthened by the recognition that patients share responsibility for making decisions about their care, including the management of information about their clinical conditions [4]. As a corollary of the principle that the patient’s personal autonomy should be respected in health care, the privacy of individual medical information is increasingly protected not just as a matter of professional ethics but also as a matter of public policy [5]. Although clinicians may sometimes chafe under the bureaucratic requirements of the Health Insurance Portability and Accountability Act (HIPAA) of 1996, most clinicians understand the importance of the patient privacy interests this law is intended to protect [6]. Few facts are as psychosocially potent as those regarding our health problems, treatments, and prognoses, or as intimately tied up with the other interests of our lives [7].

The obligation to protect the confidentiality of clinical information about individual patients extends to situations in which that information is systematically collected, combined with data from other patients, and shared for research and planning purposes. The traditional method of protecting individual privacy in such collections is to deidentify or anonymize the data so that users cannot connect any particular bits of information with the persons they describe [8]. In theory, anonymized data permanently removes those links, making it impossible for individual patients to be harmed by the disclosure of facts about them [9]. With deidentified data sets, in contrast, the end users are blinded to patients’ identities, but someone plays the role of an “honest broker” or “steward” for the data, making it possible to re-identify particular bits of data if necessary [10-12]. The crucial virtue of these data protection arrangements is their trustworthiness in patients’ eyes, and this tends to be the crux of debates over the merits of specific data protection systems [13].

The first set of challenges faced by data sets that retain any links to patient identities is the technical security of the database [14]. As clinical data sets move from locked filing cabinets into networked electronic files, the same data
security issues that retailers face—from lost laptops to online breaches—also apply to health care providers and biomedical research programs. Accidents and incursions are often occasions for disclosure and apology [15], but they do not reflect internal ethical tensions in database design or use. Other security issues do reflect such tensions, simply because the same informational richness that enables useful research also increases the risk of re-identifying patients, even in the most thoroughly anonymized data sets.

For example, one of the challenges of working with large patient data sets is the possibility of using data-mining techniques to re-identify the individuals whose health problems are being described, even after efforts have been made to sever such links. This re-identification can occur if overlapping sets of information about the same individuals are represented in different data sets that can be cross-referenced, such as DNA sequencing databases and electronic genealogical archives [16], or it can occur when a data set includes enough ancillary demographic, environmental, and geographical data to demarcate individuals even when their formal identifiers are removed [17]. Some forms of medical data, such as genomic profiles or neurological patterns, are themselves indelible individual identifiers [18]. This immediately undermines the privacy of the information, raising important confidentiality concerns for database managers and users. Because such annotation and cross-linking is crucial to the epidemiological and diagnostic utility of clinical data sets, an internal tension is created between enabling data mining to promote science or discouraging it in order to protect privacy [19].

One approach to this challenge has been to call for research volunteers who are “information altruists”—individuals who are willing to share fully identified personal medical data for any and all research purposes [20]. Empirical research suggests that the only individuals who can afford to volunteer such information are those who are well buffered from the social risks of exposing their future health vulnerabilities, so this approach may not be able to meet health care’s wider informational needs [21]. As a result, the same honest broker and stewardship models that are used to protect participant confidentiality are sometimes adapted to give proxy decision makers (such as data access committees or community advisory boards) authority to police broad consent agreements on behalf of individual participants [22].

**Group Harms**

Another reason why large biomedical databases seek governance advice from representatives of the community of patients described in the database is because group-level conclusions drawn from the data may have social implications for the whole group, including individuals who were not included in the data collection [23]. There can be group-level social implications when data are collected and organized in terms of particular social identifiers—such as family kinship, ethnicity, language, or geographical location—or when such identifiers are reported as significant factors in the results of the data analysis. For example, the promise of personalized genomic medicine depends more on the identification of genetic risk markers—which can allow health researchers to classify patients into different risk groups—than it does on being able to “tailor” interventions to a specific individual’s genome [24]. In the United Kingdom, this approach is sometimes called stratified medicine [25], which more accurately represents both its logic and its potential for social fallout. If the primary use for large medical data sets is to sort our population into strata of medical risk, that suggests that not all groups are created equal; some groups will perforce fall into higher-risk strata for particular health problems. For health care payers and providers who are concerned with containing health care costs, using genetic data to define high-risk groups opens the door to a variety of forms of genetic discrimination. As one insurance industry analyst famously wrote in 1997, “Harsh as it may sound to the ears of a society that subscribes to egalitarian principles, solidarity ends with a negative genetic test” [26].

Fortunately, the passage of state-based insurance laws and of federal laws such as the Americans with Disabilities Act of 1990, the Genetic Information Nondiscrimination Act of 2008, and the Patient Protection and Affordable Care Act of 2010 has reduced the prospect of individual exclusions from health care coverage based solely on genetic information [8]. However, laws cannot police public and professional attitudes, and to the extent that the information that emerges from large patient data sets—whether genomic, clinical, or environmental—coincides with social identifiers that already play powerful social and political roles, such as race, the stakes involved for members of such groups increase [23]. A central strategy in genomic research, for example, is to compare the genomic profiles of different groups in order to identify the variants that explain their phenotypic differences. But groups that are defined by criteria that also have important social functions—such as geographical boundaries, race, ethnicity, socioeconomic status, or genealogical ties—can be as sensitive to the social risks and benefits of scientific generalizations as can their individual members. On the one hand, by illuminating health disparities between groups, such findings can highlight and perhaps help rectify injustices in the distribution of health care resources. On the other hand, if such findings are interpreted as showing that certain health vulnerabilities are inherent to the group, they can be used to excuse health inequities as natural phenomena and possibly to stigmatize the group for its disproportionate use of health resources [27].

The problem is that preserving the medical confidentiality of health data at the group level by deidentifying or anonymizing the data of at-risk segments of the population defeats the public health and medical goals of the enterprise. Unlike individuals, groups must be “information altru-
ists” with respect to their health risks and outcomes if they are to reap the benefits of research. Thus, although some genomic researchers have tried to publish deidentified genetic epidemiological research, the usual privacy protections are unavailable at this level [28]. Instead, database managers and population researchers have turned to different levels of community engagement in managing their collections. Researchers hope that by involving representatives of patient groups in decision making about data access and dissemination, they will be better able to anticipate and avoid potential risks of group-level information disclosure, to give the affected communities more control over the uses of “their” information, and to help ensure that risks are offset by benefits to the affected community [29]. Some families, communities, and national governments have begun to assert claims of “genomic sovereignty” over samples and data from members of their groups, thus introducing powerful political, economic, and legal complications for scientists and clinicians [30].

Ethical Implications

The principal attraction of large, cross-referenced sets of health data is their potential utility in health services, population health, environmental health, and comparative effectiveness research. In fact, without access to robust data sets including information about large numbers of patients and control subjects, many important public health research questions will never be answered. When compared with the social need to address those questions, the privacy risks involved in such research seem relatively remote. After all, research with deidentified patient records and other anonymized clinical and biological data has traditionally been exempt from human research protections, on the grounds that the interests of the information sources could not be harmed. Much also remains to be done with regard to quantifying the privacy risks of biomedical data-sharing [31] and to determining the effectiveness of existing public policy protections [32]. Moreover, if the risks of group identification constitute the price that groups must pay for the benefits that could come from such research, perhaps the risks of re-identification should be the price that society asks individual patients to pay for sharing in these benefits.

This line of argument has led to a provocative refrain in the medical research ethics literature in recent years; specifically, it has been suggested that, despite our strong convictions about the importance of voluntary participation in biomedical research, perhaps the time has come to create an expectation in favor of participation [33]. Some biomedical researchers and ethicists have even suggested that patients have a positive obligation to participate in health data research and that health care institutions should be allowed to collect and disseminate identifiable clinical data without maintaining the protections traditionally afforded research volunteers, such as informed consent, the right to withdraw, and informational confidentiality [34]. One advocate of this position argues:

With millions of people suffering from common incurable diseases and with the constant threat of the development of new ones, healthcare cannot be taken for granted. Under these circumstances it should be recognized that all individuals have an obligation out of solidarity not to hinder potentially beneficial medical research that costs them nothing and is of no risk to them [34].

In some ways, the growing recognition of group interests in population-based research only propels this trend. As groups exert claims over the governance of data that describe their particular vulnerabilities and strengths, they also begin to have an interest in recruiting their membership to cultivate the use of that information for their collective benefit.

The expectation is that researchers will learn a great deal more about the genome and the human microbiome and that this new knowledge will allow medicine to tailor treatments to individuals…. The studies, however, will require ... the participation of a tremendous number of subjects.... Furthermore, to the extent that any group abstains from participation, their members will be less able to share in the rewards precisely because their genetic and microbiomic samples are absent from the pool. [35].

These arguments have already led to high-level calls for rethinking the federal policies that govern health data research [22] and to solicitations for new research regarding the confidentiality risks that such research involves [36]. For clinicians, these developments should again bring to mind the Hippocratic rationale for keeping confidences: To be effective in their work, healers need their patients’ trust. By the same token, to effectively solicit useful health data from patients, health researchers must gain the trust of their data sources, and the cornerstone of that trustworthiness has been the tradition of voluntary research participation, even in the face of demonstrable public benefit. As much excitement as there is over the promise of big data to provide a scientific revolution in health care, it may be that the real paradigm shift in this domain will be the challenges to our traditional convictions about privacy, consent, and respect for individuals. As the old-fashioned ideal of “rugged individualism” becomes increasingly strained in our heavily networked society, it will be increasingly important to remember medicine’s traditional patient-centered commitments. NCMJ

Eric T. Juengst, PhD director, Center for Bioethics; and professor, Department of Social Medicine, University of North Carolina at Chapel Hill, Chapel Hill, North Carolina.

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Spotlight on the Safety Net

A Community Collaboration

The Health Outcomes Initiative of the North Carolina Association of Free Clinics

The North Carolina Association of Free Clinics (NCAFC) is a private, nonprofit organization that provides advocacy, resource development, grant funding opportunities, training, and technical assistance for its member clinics and the uninsured individuals they serve. The 81 free clinics and pharmacies belonging to the NCAFC provide medical care, dental care, and prescription medications for low-income, uninsured, or medically underinsured people in both rural and urban locations in 79 counties across North Carolina.

In 2009 the Health Outcomes Initiative was developed by the NCAFC in partnership with the Blue Cross and Blue Shield of North Carolina Foundation to increase the capacity and strengthen the infrastructure of the free clinic network in order to enhance the clinics’ ability to provide high-quality care for underserved individuals in their communities. This initiative, which was the first of its kind among free clinic associations in the United States, began by using the NCAFC’s Annual Outcomes Survey to systematically track and report health outcomes for patients with chronic diseases. Clinics participating in the survey receive funding to bolster their work based on patient volume, health outcome gains, and improvement compared with the previous year. The overarching goal of the initiative is to develop a culture of continuous quality improvement (QI) within the free clinics by helping them collect and analyze health outcomes data and eventually implement QI activities based on these data.

In a 2012 report to the US Congress about quality incentives for safety-net providers, George Washington University used this North Carolina model as an example of financial support “driven by achievement of quality measures and improvements in same” [1]. The report notes that quality-based grant making of this sort reinforces the role that free clinics have historically played as “incubators of innovation in cost-effective, quality care” [1].

In the health care safety-net system, the collection of health outcomes data is unique and innovative; furthermore, the data show that free clinics play a prominent role in North Carolina’s safety net. In 2012, the NCAFC provided health care services worth more than $211.2 million to 91,597 patients—free of charge—through the work of 8,445 health care professionals and other community volunteers [2]. On average, $6.45 in health care was provided for every $1 spent to operate a free clinic [2]. These data show that free clinics are widely supported by communities across the state and that free clinics provide accessible health care to uninsured patients.

Beyond playing a prominent role in their communities, free clinics provide high-quality care that is on par with state and national benchmarks. In 2012, 40% of patients with diabetes seen at free clinics in North Carolina had a glycosylated hemoglobin level lower than 7% on their most recent assessment; in comparison, among North Carolina participants in the Health Resources and Services Administration (HRSA) Health Center Program, 42% of patients with diabetes met this goal [3]. Also in 2012, 65% of free-clinic patients with hypertension had a blood pressure reading lower than 140/90 mm Hg during their most recent visit; of the patients with hypertension seen at North Carolina’s 32 HRSA health centers, 60%
achieved that target in 2012 [3]. Another indicator of evidence-based practice is that 72% of free-clinic patients with hypertension who achieved adequate blood pressure control in 2012 received at least 2 additional blood pressure assessments after meeting that goal.

Before the NCAFC Health Outcomes Initiative was implemented, most clinics did not know how often they were following evidence-based practice guidelines. For example, the Wayne Action Team for Community Health (WATCH)—which operates a free, mobile, primary care medical unit—found that they had performed comprehensive foot exams for only 27% of patients with diabetes treated in 2012. Wanting to provide more foot exams for their patients, they focused their QI activities on increasing this rate by training staff members, creating reminders in the electronic medical record system, and streamlining the process of documenting that an exam had been performed. By the end of 2013, the foot exam rate had jumped to 83%. This is just one example of how clinics have improved quality of care by implementing QI strategies based on the collection and analysis of their outcomes data.

The culture of QI in free clinics began in 2009 with the implementation of data collection and continues today with quarterly reporting from 21 member clinics and with the NCAFC’s provision of QI training and assistance. The free clinics are making strides toward high-quality health care, as demonstrated by health outcomes data for the past 4 years and their active efforts in the QI program. By 2015 all health outcomes data from participating clinics will be submitted quarterly. By getting results throughout the year, clinics will be better able to implement continuous QI. Data collection through the Annual Outcomes Survey will continue to play a crucial role as the state’s safety-net system plans for the changing future of accountable health care, and as free clinics seek to prove that they provide essential health care for uninsured individuals across the state. NCMJ


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With provider payments being adjusted for performance and emphasis being placed on value-based care, large health care systems are already developing the resources necessary to pursue quality improvement (QI) in their practices. This article explains why smaller and/or rural practices also need to learn about and implement QI.

In 2001 the Institute of Medicine of the National Academies published a landmark report titled *Crossing the Quality Chasm: A New Health System for the 21st Century* [1]. This report forced us to take a closer look at significant deficiencies in the quality of our nation’s health care. Now, more than a decade later, US health care providers are starting to be held accountable for the care they deliver, as health care payers are refusing to shoulder the burden of increasing costs with no improvement in quality or patient satisfaction. Echoing a definition of quality provided by the Agency for Healthcare Research and Quality (AHRQ), Community Care of North Carolina (CCNC) has long promulgated the idea that its networks should deliver the right care, to the right patient, at the right time, in the right way to achieve the best possible results. That sentiment has now become a clarion call for quality.

The current fee-for-service paradigm, which rewards quantity above quality, is dying as health care payers increasingly cannot and will not pay for care that is not accountable. So where does this leave North Carolina’s health care providers? What changes can we expect in the future?

**Penalties for Failing to Adopt QI**

The federal government has taken the lead in promoting quality of care with certain provisions of the Patient Protection and Affordable Care Act of 2010 that emphasize wellness and prevention. In conjunction with these changes, physician practices are being challenged to learn and apply principles of quality improvement (QI); those who do so will receive incentives for good performance, or they will be penalized if they choose not to participate [2]. Over the next 3–5 years, more and more provider payments will be “at risk” as more emphasis is placed on value-based care.

One federal guideline that promotes quality is the Physician Quality Reporting System (PQRS), which offers incentive payments to eligible providers who report data on quality measures for professional services covered by Medicare Part B. Eligible providers who satisfactorily submit PQRS quality measures for 2014 will qualify to receive an incentive payment of 0.5% for covered services provided during the reporting period; those who do not satisfactorily report these quality measures for 2014 services will be subject to a 2% payment adjustment in 2016 [3].

Second, beginning in 2015, payment rates under the Medicare physician fee schedule will be subject to a value-based payment modifier (VBPM) for groups of 100 or more eligible professionals who submit claims to Medicare under a single tax identification number. By 2017, this modifier will be implemented for all physicians participating in fee-for-service Medicare. The VBPM is based on the physician’s performance 2 years earlier (eg, application of the VBPM in 2015 will be based on performance in 2013). Eligible professionals may avoid a 1% reduction in Medicare reimbursement payments by successfully participating in the PQRS [4].

Third, on October 1, 2014, the *International Classification of Diseases, 10th Revision, Clinical Modification* (ICD-10-CM) is scheduled to become the code set mandated by the Health Insurance Portability and Accountability Act (HIPAA) for reporting diagnoses and conditions. For dates of service on or after October 1, 2014, providers will have to code all claims using ICD-10-CM in order to receive payment from Medicare, Medicaid, or any private payer, and failure to do so may result in denial of claims [5]. [Editor’s note: At the time of publication, the Senate had passed legislation that would delay the transition to ICD-10-CM; if signed into law, it would postpone implementation of ICD-10-CM by at least 1 year.]

Fourth, practices that begin to participate in Medicare’s electronic health record (EHR) incentive program in 2014 can still earn up to $23,520 per physician in cumulative payments over 3 years [6]. In 2015, there will be a 1% payment penalty for providers who are eligible but who decide not to participate [2].
cians and practices can also earn rewards for meeting cer-
revenues in an APM that involves 2-sided financial risk and
2021 for practices that have a “significant” share of their
Model (APM). To encourage participation, the legislation
changes and proper alignment of incentives are necessary
[NCQA] or The Joint Commission).
possible score for this category.
specialist practicing in a PCMH would receive the highest
criteria in the “clinical practice improvement activities”
ful use. It is worth noting that many of the performance
zation); clinical practice improvement activities; and mean-
compensation is encouraged through a variety of programs that mandate working with management and quality
to define and improve quality metrics.
3–5 years toward a goal of having 40%–50% of provider’s
recognizes the valuable role of PCMHs. As part of the process
of qualifying as an APM, PCMHs that demonstrate to CMS
that they can improve quality without increasing costs, or
can decrease costs without decreasing quality, can receive
a 5% annual bonus payment without having to take direct
financial risk (2-sided risk).
Implementing QI in Practice
Currently, CCNC is being called upon to participate in payment reform initiatives for Medicaid. CCNC is looking
to incentivize physician participation with CCNC care management programs and to align with other payer initiatives.
These initiatives include PCMH recognition, successfully navigating meaningful use, and the Blue Quality Physician
Program (BQPP) of Blue Cross and Blue Shield of North Carolina. CCNC also plans to incentivize enhanced quality
activities, such as working with care managers and QI teams on projects involving key performance indicators and/or
quality measurement and feedback data.
Commercial payers and hospital systems are also encouraging physicians and providers to participate in quality pro-
grams that mandate working with management and quality teams in order to improve care, decrease costs, and improve
patient satisfaction. Many are also requiring providers to participate in value-based care programs in which at least a
portion of their compensation will be through per-member-month payments or a portion of their salary will be withheld until certain quality metrics are met.
Some of the larger accountable care organizations (ACOs) in North Carolina are moving rapidly over the next 3–5
years toward a goal of having 40%–50% of provider’s salaries contingent on quality, and many ACOs are already
making the shift to value-based care and shared-savings contracts. A cultural shift is also occurring in these organi-
zations: Instead of solo practitioners focusing on their own performance and claiming that they do not have to be wor-
ded about quality, providers in larger organizations now
recognize that they rise or fall based on their collective per-
formance. Also, employed physicians in larger organizations
will need to comply with organizational goals or face pos-
sible consequences, and most hospitals and ACOs have QI
teams that work with the practices within the organization
to define and improve quality metrics.
Where does this leave independent physician groups, particularly small groups of 1 to 4 providers who prac-
tice in rural areas? The same forces that are driving larger
practices and systems to focus on quality are beginning to
affect smaller practices as well. Some smaller practices may
believe that they have more time to decide whether they are
willing to learn how to assess quality metrics, or they may
have feelings of “warning fatigue,” because physicians have
been hearing for years about the coming wave of account-
ability but have not yet seen much proof of it. Although
these smaller practices can keep QI at arm’s length for now, all will eventually have to join the quality movement.

Providers can refuse to see this coming change, allow practice performance to languish, and pay financial penalties. Or providers can embrace the coming changes—with the help of people like the members of CCNC’s quality teams, working in collaboration with groups such as the North Carolina Area Health Education Centers (AHECs)—and they can work to incorporate these changes into their daily work flows.

Providers may be asking themselves whether now is the time to become recognized as a PCMH or as a patient-centered specialty practice (PCSP). A recent article in the Journal of the American Medical Association by Friedberg and colleagues [12] casts doubt on the effectiveness of PCMHs in reducing utilization and costs. However, it should be noted that the PCMHs in this study met the 2008 NCQA standards rather than the newer standards; NCQA updated its standards in 2011 and again in March 2014. As PCMH standards continue to evolve, more emphasis is being placed on alignment with meaningful use, outcomes, and integrated care.

Evidence for the validity of the PCMH model continues to mount and to be codified in research. A recent NCQA white paper [13] summarized several studies that found that the PCMH model improves quality of care, continuity of care, and the patient experience, and that it can lower costs through better prevention and disease management. Likewise, the most recent annual report of the Patient-Centered Primary Care Collaborative [14] analyzed 13 peer-reviewed studies and 7 industry studies and found cost savings and use reductions in about 60% of 20 PCMH evaluations. In an even more recent article by Higgins and colleagues [15], the PCMH model was associated with significantly reduced costs and utilization for those members at highest risk, particularly with respect to inpatient care.

The magnitude of savings and quality improvements in these PCMH pilot programs and initiatives depends on a range of factors, including the program design, enrollment numbers, payer mix, target population, and implementation strategies. In addition, one of the hallmarks of successful PCMH projects is the provision of financial and/or technical assistance to the practices involved. Making sure that patients are risk-stratified contributes to cost savings by giving practices the ability to target certain populations, such as those who are the most seriously ill or are high utilizers of care. The inclusion of patients as advisers or navigators is another feature of the best PCMH models, as is the presence of QI systems that include personnel educated in QI techniques and theory.

Future medical home initiatives will need to continue to be refined to produce better results and to further delineate the specific metrics and practice interventions that have the greatest impact on patient care. From my experience with a multipayer initiative in the western part of North Carolina, I found that this is particularly true for smaller, rural practices. In such settings, spending time and resources on initiatives that do not improve care comes at a very high premium. Aiming for PCMH recognition and/or starting a quality project might be a practice’s first step.

I predict that both the private and public sectors will continue to see growing value in the PCMH model. This model has been shown to play a foundational role in the development and spread of the ACO model, and with the advent of PCSPs, the PCMH model has also shown its value in the growth of the medical neighborhood, as specialty practices begin to understand their part in cost-containment and quality. Success for specialists must begin with a strong connection to their primary care colleagues. Recent research has borne out the idea that the nation’s leading and highest-performing ACOs find primary care and the PCMH model to be integral to their success. Thus the PCMH model is seen as a starting point from which to move toward broader application of the Pioneer ACO Model [16].

My abiding hope is that Congress will continue to address the flawed SGR method and the other aspects of the Medicare payment system that reward quantity, waste, redundancy, and lack of accountability. We are rapidly moving toward a payment system that rewards quality, innovation, and efficiency, and that incentivizes physicians and their care teams to transform their practices to become PCMHs. This will become even more important as providers begin to enter into more gain-sharing contracts and risk-sharing practice arrangements such as ACOs. Organizations such as CCNC and the AHECs will be identifying the practices that want to work in these areas, those that are interested in becoming recognized as PCMHs, and those that are willing to meet and discuss their data and see where they need to improve. These organizations will then work with the QI practice team to move the needle toward improved outcomes, better care, higher patient satisfaction, and lower cost. NCJ


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