USING DATA, QUALITY OUTCOMES & TRANSPARENCY

Improving Healthy Outcomes of Vulnerable New Mexico Children, Families and Communities

Blue Print for Health New Mexico

CON ALMA HEALTH FOUNDATION
KELLOGG STRATEGIC PLANNING GRANT

By
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Policy Connections West

August 2011
“The Blueprint for Health New Mexico – Designing Better Health” is a project of the New Mexico Con Alma Health Foundation through a six month strategic planning grant from the W.K. Kellogg Foundation awarded to help guide New Mexico’s implementation of the national Patient Protection and Affordable Care Act (ACA). Con Alma serves as a convener of stakeholders and experts to developed shared goals, leverage federal funding and build a strategic blueprint to improve health outcomes for vulnerable New Mexico children, families and communities with emphasis on four counties: Bernalillo, Dona Ana, McKinley and San Juan.

Con Alma’s Resource Team of experts initiated a work plan addressing ACA requirements and which would inform a statewide comprehensive strategic health care reform implementation planning process through a Blueprint Advisory Network. Con Alma Health Foundation requested that Policy Connections West, a New Mexico nonprofit organization, define and analyze the data requirements in the ACA that will inform the effective implementation of the ACA and elucidate the opportunities for quality outcomes, transparency to the public and elimination of health disparities in vulnerable families and children.

Several provisions for implementing the ACA require integrating and aggregating current data collection points or collecting new data for new systems. The most obvious of new systems and what drives much of the ACA insurance reforms is the Health Benefits Exchanges or Health Insurance Exchange (HIE). States will need data elements which include race, ethnicity, primary language, sex and disabilities.

IT processes in most states are outdated and difficult to modify. So, the ACA anticipates that states must develop and refine data sharing between state entities and the federal government for information on income and citizenship. The ACA requires the collection of data to determine if programs to reduce health disparities are working.

Major new provisions of the ACA which require new or expanded data collection are set out in the following chart: “Patient Protection & Affordable Care Act Major Sections Relating to New Data Collection”.
## Patient Protection & Affordable Care Act (ACA): Major Sections Relating to New Data Collection

<table>
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<th>ACA Section</th>
<th>Title</th>
<th>General Provisions</th>
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| 1001        | Immediate Improvements of Health Care Coverage                        | All non-granfathered insurance plans to submit & make available to the public  
All plans must submit to the Secretary and State insurance commissioner and make available to the public the following information in plain language:  
Claims payment policies and practices  
Periodic financial disclosures  
Data on enrollment  
Data on disenrollment  
Data on the number of claims that are denied  
Data on rating practices  
Information on cost-sharing and payments with respect to out-of-network coverage |
| 1001        | Bringing down the cost of health care                                 | …enhance the use of health care data to improve quality, transparency, and outcomes.                                                                                                                                    |
| 1002        | Grants for health insurance consumer assistance or ombudsman          | State must collect and report data on the types of problems and inquiries encountered by consumers. The data shall be used to identify areas where enforcement action is necessary… |
| 1003        | Review of rates for consumer value                                    | HHS Secretary reviews rate setting procedures. States to provide data and documentation to establish effective review process.                                                                                          |
| 1311, 1312  | Affordable Choices-Health Benefit Plans                              | Grants of $1 million per state. Required needs assessment, research, demographics, activities, evaluation criteria and other data collection needs for the exchange design and operation.  
When exchange designed and implemented states held to submission of data as stated by HHS guidelines/regulations and PPACA provisions.  
To establish an exchange the state must have data and performance measurements on all exchange elements, assure transparency and available to the public, allow for consumer satisfaction data collection; and ensure data assists in integrating data from multiple state and federal sources.  
GAO oversight of exchanges in 5 years to conduct an ongoing study of Exchange activities and the enrollees in QHPs offered through Exchanges, including data on cost, affordability, data on |
| 1302, 1303  | Establishment of Qualified Health Plans                               | Be accredited with respect to local performance on clinical quality measures (e.g., Healthcare Effectiveness Data and Information Set (HEDIS), Consumer Assessment of Healthcare Providers and Systems (CAHPS)) |
| 1311, 1413  | Streamlined Health Program Enrollment                                 | Data standardization for ease of enrollment in exchange health plans. Standardize data reporting on pricing of plans, quality, benefits, etc.                                                                               |
| 1411        | Procedures for determining eligibility for Exchange participation, premium tax credits and reduced cost sharing | Develop a program for the determination of eligibility for Exchange participation, subsidies, and exemptions. Exchanges must collect specified relevant information for determining eligibility from the individual mandate. |
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1412 | Advance determinations and payment of premium tax credits and cost-sharing reductions | Establish a program for the advance determination of income eligibility for individuals applying for subsidies through the Exchange.
1413 | Streamlining of procedures for enrollment through an Exchange and state Medicaid, CHIP, and health subsidy programs | Develop a single streamlined form that may be used in applying for all applicable state health subsidy programs. This form can be filed online, by mail, or by telephone.
1561 | Health information technology enrollment standards and protocols | Develop interoperable and secure standards and protocols that facilitate electronic enrollment of individuals in Federal and State health and human services programs.
4302 | Data Collection Standards for Race, Ethnicity, Primary Language, Sex, and Disability Status | Proposed rules out for comment. Evidence based standards proposed. States will need data to effectively operate the Exchanges.
10332 | Availability of Medicare Data for Performance Measurement | Measure and publicly report information about the performance of physicians, hospitals, and other health care providers is to improve health care quality and control costs. Incentivize quality measurement and reporting and to enable more informed consumer decision-making, transparency, accountability.
3013, 3014, 3015 | National Strategy to Improve Health Care Quality | Codifying a series of provisions which together comprise a national-level approach to the improvement of health care quality, quality measurement, and the use of quality data; Incentivizing the development or implementation of, or facilitating, a number of health service delivery reforms; Targeting quality improvement reforms across the spectrum of payers, including private health insurers, Medicare and Medicaid; ensure public reporting of quality data through a strategic plan to include quality measures in federal programs.
5103 | Healthcare Workforce Program Assessment | Utilize a longitudinal evaluation and reporting data and reports to a national database.
3132 | Hospice Reform | HHFS to collect additional data and information as appropriate to revise payments for hospice care. Data may include information on charges and payments; number of days of hospice care for Part A beneficiaries; number of days attributed to each type of service; cost of each type of service; and other issues.

Provisions of the ACA require that the new data requirements be placed within the public domain and be transparent and available to consumers. All in all, the new data requirement in the ACA should be the driver to make solid and lasting improvements in the health care delivery system.

States can use their existing and planned health information exchange infrastructure to more efficiently comply with the ACA’s data provisions. States must work out IT business operations and infrastructure to coordinate the flow of eligibility and enrollment information among Medicaid, CHIP, and the exchange. This means that states need a realistic but effective timeline for instituting operations of the Exchange and align ACA data collection and reporting systems with that timeline.

ACA transparency elements will require public reporting on Exchange activities and operation as well...
as standardized data reporting on all HIE functions. Consumers and small employers will be informed by objective information and easily interpreted health care and insurance coverage data. Through HIE data elements consumers and small employers can be assured of fair and impartial treatment and objective information for them to assess plan eligibility, benefits, performance, rates, and performance indicators.

New Mexico’s Exchange Planning Grant funding has provided for a “GAP” analysis of IT support systems across health services delivery, human services, and health care regulatory agency sectors. This will also include an analysis of infrastructure needs to fulfill ACA data collection requirements and an IT business operations plan for ACA compliance. The new application for the Affordable Insurance Exchange Establishment grant through HHS will further expand the NM Exchange IT systems and data collection requirements. Development of these systems will need to follow the ACA minimum functions of the Exchange.

An issue that’s not often discussed is whether aspects of the data system that consumers can access are realistically “accessible” to persons with disabilities. Will there be, for example, data collection and website systems under which consumers with disabilities can without much difficulty apply on line for benefits? Assistive technologies should be a planned and designed element in the Exchange. These may include training and support, physical infrastructure accommodations, and conversion of Exchange information and materials into accessible format such as Braille and screen readable text, adaptive computers and other technology-based disability accommodations.

Effective use of data at the state level can support the establishment of health care quality indicators and outcome measurements for the population at large, and in particular vulnerable children, families and communities. Moreover, linking federal, state and local data sources to address health disparities for vulnerable populations should be a major planning and design factor as the state moves toward ACA implementation and develops its Exchange criteria.

Across the country, there are efforts based in States and regional collaboratives that are at the cutting edge of measuring quality performance outcomes. There is no need for any state to start from scratch when advancing quality outcomes or addressing health disparities and collecting data to support reporting and measurement of quality or health disparities indicators. A myriad of federal resources as well as New Mexico health care reports have been produced over the last several decades to design and put into practice health quality indicators and measures and define how to undertake progress on the elimination of health disparities. The big effort for New Mexico will be to aggregate these resources, refine them into usable data functions for the state, and make them available for public consumption and easy understanding.

Section 4302 (Understanding health disparities; data collection and analysis) of the ACA amends the Public Health Service Act to expand the current requirements for the collection and analysis of health disparities data. All federally funded health programs and population surveys will be required by 2013 to collect and report data on race, ethnicity, primary language, and other indicators of disparity. This provision strengthens data collecting and reporting mechanisms in Medicaid and the Children’s Health Insurance Program, bringing them up to the same standards as Medicare.

Because all this information and data can be overwhelming, now is the time for the State of New Mexico to renew its commitment to collaborative efforts to aggregate data for quality outcome indicators, track efforts to eliminate health disparities and provide transparency to the public.
Opportunities for New Mexico

Management - The Interagency Collaboration (NM Health Reform Leadership Team)

New Mexico continues its Health Reform Leadership Team established after the passage of the ACA. To its credit the group has monitored ACA activities, moved to take advantage of funding and grants from federal agencies and philanthropy. The Leadership Team has provided for stakeholder input and developed some outreach strategies through contractors and agency representatives.

The State now has the opportunity with its Leadership Opportunities for New Mexico Team to expand its consumer and provider outreach through establishing foundational principles on data collection and transparency and the relationship to the design and implementation of the Exchange. The State can use its work on its human services IT GAP analysis to plow new ground on data transparency and communicate how it will address quality measurement data in new ways that call attention to racial and ethnic disparities.

Transparency

Openness is a critical factor to achieving transparency in health care reform implementation. It is an attitude of the governmental organization which allows its functions to be readily accessible to the public. It is a willingness to be forthright with the public’s trust.

Health care reform provides the state and consumers the ability to build a trust relationship leading to quality health care for all.

Don't Reinvent the Wheel/Build on What Has Been Started

New Mexico and federal agencies have developed quality indicators to improve health outcomes of its populations including health disparities in racial and ethnic minorities. Similarly as with its IT GAP analysis the State can also promulgate a GAP analysis current data on health outcome indicators from counties, community health centers, local governments, and county health collaboratives.

Designing for the ACA also provides a unique opportunity for the State to utilize the expertise of local communities which understand what happens on the ground between the health care delivery system and consumers in their communities. Organizations and consumers in local communities have developed strong data collection points and interact on a daily basis with people and providers.

Develop transparency and data guidelines and working principles for use across sectors and in particular for implementation and operation of the HIE. Collaborate with current stakeholders and seek broader perspectives from local communities. Data from HIE and other health reform activities should be transparent, easily available for review, and set out in multiple sources of consumption.
Opportunities for New Mexico (continued)

Utilize Current County & Community Data/Keep It Current

There should be a commitment to take current locally collected county and community data and include indicators of racial and ethnic health disparities at a community level and continue updates to make this data relevant and current.

One of the best methods to interface at an on the ground community level and keep data relevant is through community based participatory research. While this requires some training of community and workers on the ground many New Mexico counties and health collaborative know and understand this participatory research concept. Once established, it can be key to design and implementation of major provisions of the ACA. When given the opportunity, most community health providers and leaders will embrace the chance to establish a relationship that makes their health care challenges relevant to policy makers. Community based participatory research allows communities to share their knowledge and experiences and share their historical social, environmental and health outcomes data and information collected over the decades.

Elimination of Health Disparities

New Mexico has its “Racial and Ethnic Health Disparities Report Card” which has been a good start to documenting New Mexico issues and establishing some indicators for addressing health disparities. The Report Card does not transcend to higher plane of ACA planning, such as how health disparities can be focused on in Exchange operations. Having a commitment to lowering health disparities requires setting up a time frame to implement strategies to eliminate them, utilizing data from the Exchange, tapping into federal data collection tools, and creating new aggregated state data tools for determinants of health.

Some states conduct their own population health disparities surveys, which tend to have more in-depth information about health indicators and disparities outcomes. They may include such indicators as health insurance coverage and related issues such as health status and use of services. The ACA provides a backdrop to begin a health disparities population survey in New Mexico and it can also be a promising source of data for modeling the impact of policy changes for eliminating racial and ethnic health disparities.

All this is not easy and necessitates a commitment to long-term work on reduction and elimination of health disparities. Those working in health care reform should acknowledge these difficulties and deconstruct the work so that this goal does not feel unbearable and unachievable.
Acknowledgments

Social and Environmental Determinants of Health are Real

As with quality indicators and outcomes, many states and federal agencies have developed criteria of social and environmental determinants of health. Looking at the NM county health collaborative work plans over the last decade, it is clear that social determinants are a big part of each plan and discussion of the health of various communities around the state. The NM DOH also in its presentation of “Health Status in New Mexico 2011” has identified social indicators of health, although the agency does not acknowledge them as such. For example, annual income, self reported health status by educational breakdown, binge drinking by education and income, risk behaviors by family relationships.

Other social determinants will track the health needs and quality outcomes for disabled populations. For instance, community accessibility including transportation to and from health providers and home health care, where there is a continuing lack of public transit in all geographic areas of the state, particularly in rural communities.

The next logical step can be to acknowledge, identify and set standards and metrics for social and environmental determinants of health within the context of vulnerable communities, families and children. It is a matter of building on what has already been started.

Track the Impacts of the ACA in New Mexico

Commencing this evaluation process during early design of the Exchange and planning for ACA implementation generally is critical to affecting quality outcomes, eliminating health disparities and presenting data in a transparent and thoughtful way to policymakers and the public about the impacts of health reform.

A structured data and evaluation strategy can compile meaningful information and highlight key quality outcome measures and make technical documentation accessible and transparent.

New Mexico has some unique opportunities to work with current philanthropic endeavors in the State that will bring together stakeholders from distinct and diverse backgrounds and communities. These stakeholder networks can build an evaluation and data collection assessment of ACA impacts on health care delivery strategies and health care reform requirements.
pronunciation: [dey-tuh, dat-uh, dah-tuh]

noun
1. a plural of datum.
2. (used with a plural verb) individual facts, statistics, or items of information: These data represent the results of our analyses. Data are entered by terminal for immediate processing by the computer.
3. (used with a singular verb) a body of facts; information: Additional data is available from the president of the firm.

*Function: (noun plural but singular or plural in construction) factual information (as measurements or statistics) used as a basis for reasoning, discussion, or calculation: Data is plentiful and easily available; Data on the incidence of Lyme disease.
Data:
Why the Emphasis in Health Care Reform?

We are bombarded with data everyday that we process as we make our way through our daily activity routines. Without this “factual information” and “body of facts” incoming to our senses, we would be unable to function in this increasingly technologically advanced world. But in its simplest terms, data keeps our brains and senses alive and functioning at a basic human level of awareness in ourselves and our environment.

Data it is said is vital to providing appropriate health care and improving health outcomes for our people. And, if you think of it, this is most likely borne out by historical human experiences at its most simple terms. I look at my child, I see his face is red, I feel his very hot stomach, I watch his face grimace with discomfort, I see he is not positively responsive to normally joyful stimuli. I combine this physical data from all his different physical sources. I aggregate this physical data from his body, his physical environment, my responses to him, and his responses to his social surroundings. Combining this data from his different physical attributes and aggregating the data across physical, mental and environmental systems surrounding him, I conclude he is not acting or looking “in his normal state.” I begin to quantify the data to conclude the seriousness of his physical being. I conclude I should take some positive measures to get my child back to “his normal wellness state of being.”

As we talk about the ACA requirements of new “data collection” elements, aggregation and combining data to monitor population health, eliminate health disparities and identify priorities for health improvements, establish metrics for quality improvements, and develop quality and transparency indicators, and all those other seemingly complicated ACA provisions, we should remember and come back to our basic human example of why we want to gather and use our new data.

Let us ask ourselves some basic questions about data collection and aggregation, health indices of quality and transparency and public health improvement measurements as the state moves toward planning and implementation of the ACA.
Several provisions for implementing the ACA require integrating and aggregating current data collection points or collecting new data for new systems. The most obvious of new systems and what drives much of the ACA insurance reforms is the Health Benefits Exchanges or Health Insurance Exchange (HIE). States will need data elements which include race, ethnicity, primary language, sex and disabilities. (Department of Health and Human Services, Notice of Availability of Proposed Data Collection Standards for Race, Ethnicity, Primary Language, Sex, and Disability Status Required by Section 4302 of the Affordable Care Act. Federal Register / Vol. 76, No. 126 / Thursday, June 30, 2011 / Notices)

New data under the ACA provisions will be collected on wellness programs, the prevalence of chronic diseases, the health care workforce, review and collection of health insurance rates by state commissioners and a myriad of quality metrics. (Weill, Allan. "State Policymakers’ Priorities for Successful Implementation of Health Reform." National Academy for State Health Policy. www.nashp.org May 2010.)

The ACA requires the collection of data to determine if programs to reduce health disparities are working. To achieve the goals of the ACA in April 2011, HHS released two strategic plans to reduce health disparities and achieve health equity in the Nation: HHS Action Plan to Reduce Health Disparities, outlines goals and actions to reduce health disparities among racial and ethnic groups, and states that the data collected will improve health care delivery and public health outcomes. (Weill, Allan. "State Policymakers’ Priorities for Successful Implementation of Health Reform." National Academy for State Health Policy. www.nashp.org May 2010.)

Information Technology (IT) processes in most states are outdated and difficult to modify. So, the ACA anticipates that states must develop and refine data sharing between state entities and the federal government for information on income and citizenship. For instance, enrollment and eligibility processes still have paper based procedures and are burdensome for the potential enrollee as well as those who assist them. Under the ACA, eligibility enrollment data information systems must come together in real time to provide potential enrollees to governmental health care programs and to the health insurance exchanges with clear choices regarding their health coverage options. (Weill, Allan. "State Policymakers’ Priorities for Successful Implementation of Health Reform." National Academy for State Health Policy. www.nashp.org May 2010.)

So What Does the ACA Require in New Data?

If we cannot answer these questions or provide a reasonable rationale for doing what we are doing to best implement the ACA, we are putting our goal of improving health outcomes at risk.

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ethnic minorities; the National Stakeholder Strategy for Achieving Health Equity, goals and objectives for public and private sector initiatives and partnerships (National Partnership for Action) to help racial/ethnic minorities and other underserved people reach their full health potential. The strategy with input from individuals and organizations throughout the country was coordinated by the HHS Office of Minority Health. The HHS Disparities Action Plan discusses four overarching HHS Secretarial priorities to address health disparities reductions and coordination of federal efforts. One such priority is to “increase the availability, quality, and use of data to improve the health of minority populations.” (DHHS. “Action Plan to Reduce Racial and Ethnic Health Disparities: A Nation Free of Disparities in Health and Health Care. April 8, 2011.)

In May 2011, the Center for Medicare & Medicaid Services (CMS) published its Guidance for Exchange and Medicaid IT Systems, Version 2.0. The stated purpose “is to assist states as they design, develop, implement, and operate technology and systems projects related to the establishment and operation of Health Insurance Exchanges as well as coverage expansions and improvements under Medicaid and the Children’s Health Insurance Program (CHIP), and premium tax credits and cost-sharing reductions under the Affordable Care Act.” The IT Guidance also states that it provides national direction to assist states to:

- Achieve interoperability between IT federal and state data components during eligibility and enrollment through the HIE, Medicaid, CHIP
- Provide simple and seamless IT to identify those who qualify for HIE, tax credits, cost sharing reductions, Medicaid or CHIP
- Support and enable IT business operations and the processes for health care coverage through Exchanges
- Ensure the development of IT solutions and approaches that will work in all states to meet key business objectives

CMS makes it clear in their guidance that it is just that. It does not intend to impose a “single IT solution on individual states.” DHHS, CMS, Guidance for Exchange and Medicaid Information Technology (IT) Systems 2 Version 2.0 May, 2011. However, it would behoove each state to utilize the guidance because it will not only provide seamless federal/state interoperability for IT implementation of the ACA but will allow states to also develop state-to-state interoperability. This can assist portability of health insurance plans and allow for less complicated opportunities for developing regional Exchanges.

The ACA (section 10332) takes a significant step by expanding HHS’ authority to release Medicare claims data to organizations that meet certain requirements for performance measurement and reporting. HHS/CMS is only authorized to release the data to organizations that meet very prescriptive requirements (privacy and security of the data). Organizations must agree to performance measures and release reports approved by CMS. This program will be of assistance to multi-stakeholder community organizations, states and local health collaboratives that are working to produce and report provider performance information in their communities. (Thorpe, Jane. “Release of Medicare Data for Performance Measurement.” Health Reform GPS. The George Washington University Hirsch Health Law and Policy Program & the Robert Wood Johnson Foundation. www.healthreformgps.org.)

Section 1561 of the ACA requires HHS, in consultation with the Health Information Technology (HIT) Policy Committee and the HIT Standards Committee to develop interoperable and secure standards and protocols that facilitate electronic enrollment of individuals in federal and state health and human services programs. These Committees in May 2011 submitted recommendations, which seek to encourage adoption of modern electronic systems and processes that allow a consumer to seamlessly
obtain and maintain the full range of available health coverage and other human services benefits. Recommendations state that health IT systems should use a set of standardized Web services that could also support the eligibility determination process across federal and state human service functions. Health IT systems should:

- Feature a transparent, user friendly online process so consumers can make informed decisions about applying for and managing benefits;
- Accommodate the range of user capabilities, languages and access considerations;
- Offer seamless integration between private and public insurance options;
- Connect consumers with health coverage and all other federally funded human services for ease of enrollment;
- Provide strong privacy and security protections.

The table below entitled, PPACA Major Sections Relating to New Data Collection, provides for a listing of the major provisions of the ACA that will require new data collection. This list highlights the sections but is not all inclusive since it is clear that implementing the ACA will require most states to extensively modify the their IT human services and insurance regulatory to best accommodate consumer interface and HIE operations.

### PATIENT PROTECTION & AFFORDABLE CARE ACT (ACA): MAJOR SECTIONS RELATING TO NEW DATA COLLECTION

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<td>3013, 3014, 3015</td>
<td>National Strategy to Improve Health Care Quality</td>
<td>Codifying a series of provisions which together comprise a national-level approach to the improvement of health care quality, quality measurement, and the use of quality data; Incentivizing the development or implementation of, or facilitating, a number of health service delivery reforms; Targeting quality improvement reforms across the spectrum of payers, including private health insurers, Medicare and Medicaid; ensure public reporting of quality data through a strategic plan to include quality measures in federal programs.</td>
</tr>
<tr>
<td>5103</td>
<td>Healthcare Workforce Program Assessment</td>
<td>Utilize a longitudinal evaluation and reporting data and reports to a national database.</td>
</tr>
<tr>
<td>3132</td>
<td>Hospice Reform</td>
<td>HHS to collect additional data and information as appropriate to revise payments for hospice care. Data may include information on charges and payments; number of days of hospice care for Part A beneficiaries; number of days attributed to each type of service; cost of each type of service; and other issues.</td>
</tr>
</tbody>
</table>
Provisions of the ACA require that the new data requirements be placed within the public domain and be transparent and available to consumers. But it is not only general consumers who will utilize this data for pricing health insurance, but providers interested in enhancing quality outcomes for their patients, small employers who are interested in extending health benefits for their employees, communities which work to address the health care needs among the most vulnerable populations can utilize health disparities data, and all those purchasers of health insurance and health care services generally. All in all, the new data requirement in the ACA should be the driver to make solid and lasting improvements in the health care delivery system.

IT systems should be able to generate data in support of performance management, public transparency, policy analysis, program integrity, and program evaluation.

Centers for Medicare and Medicaid Services, DHHS

The federal law effects a tremendous simplification in Medicaid eligibility—moving to standards based on modified adjusted gross income as defined in the tax code. States will have to develop and refine data sharing between all eligibility criteria and the federal government for information on income and citizenship. These information streams must come together in real time to provide potential enrollees with clear choices regarding their coverage options. With guidance from the federal government, states must completely redesign their eligibility systems. (State Health Access Data Assistance Center (SHADAC). 2011. “Monitoring the Impacts of Health Reform at the State Level: Using Federal Survey Data.” Brief #24. Minneapolis, MN: University of Minnesota.)
pronunciation: [kwol-i-tee]

noun
1. a: peculiar and essential character, NATURE: Her ethereal quality. b: an inherent feature, PROPERTY: Had a quality of stridence, dissonance. c: CAPACITY, ROLE: In the quality of reader and companion.
2. a: degree of excellence, grade: The quality of competing air service. b: superiority in kind: merchandice of quality.

adjective
1. being of high quality
Data, Transparency & Quality Outcomes: Significance of the Health Insurance Exchange

If the Health Insurance Exchange is to be transparent and openly accessible to small employer groups and consumers generally, then insurance plan pricing, costs and insurance plan utilization, program enrollment, consumer complaints, and other insurance plan information must be collected, compiled and disseminated in an accessible and comprehensible way through the HIE.

States can use their existing and planned health information exchange infrastructure to more efficiently comply with the ACA’s data provisions. States must work out IT business operations and infrastructure to coordinate the flow of eligibility and enrollment information among Medicaid, CHIP, and the exchange. This means that states need a realistic but effective timeline for instituting operations of the Exchange and align ACA data collection and reporting systems with that timeline.

The ACA outlines an Exchange infrastructure that can help states do the following:

- §1343 – Impose the required risk adjustment charges and distribute corresponding credits to health plans.
- §2701 – Voluntarily provide information on health care quality for Medicaid eligible adults using standardized, national measures.
- §4302 – Collect required data for Medicaid and CHIP beneficiaries on race, ethnicity, sex, primary language, and type of disability in order to better understand disparities.
- §5102 – Better understand their current health care workforces and plan for future workforce needs through a State Healthcare Workforce Development Grant.

(National Academy for State Health Policy, www.statereforum.org/taxonomy)
IT systems should be simple and seamless in identifying people who qualify for coverage through the Exchange, tax credits, cost-sharing reductions, Medicaid, and CHIP.


ACA requires data matching in the HIE for ease of enrollment, allowing a consumer to utilize only one application for enrollment in any program for which they may be eligible. State Exchanges will be upgrading data collection and information technology (IT) systems and will set HIE business operations to ensure transparency and ease of use for consumers. Some questions to be asked by states as they begin to develop their electronic data matching to determine eligibility are:

▷ How do we minimize information required on an electronic application?
▷ Does our state Medicaid agency already conduct data matching with the Social Security Administration to verify applicants’ citizenship?
▷ Does the state use data matching with any other federal databases or between means-tested programs like WIC, SNAP, TANF, or the Free and Reduced Price School Meals Program?
▷ Do we as a state have the capacity to electronically match data with other state agencies, such as the Department of Motor Vehicles, state vital statistics, or the state treasurer’s office?

ACA transparency elements will require public reporting on Exchange activities and operation as well as standardized data reporting on all HIE functions. Consumers and small employers will be informed by objective information and easily interpreted health care and insurance coverage data. Through HIE data elements consumers and small employers can be assured of fair and impartial treatment and objective information for them to assess plan eligibility, benefits, performance, rates, and performance indicators.
New Mexico’s Exchange Planning Grant funding has provided for a “GAP” analysis of IT support systems across health services delivery, human services, and health care regulatory agency sectors. This will also include an analysis of infrastructure needs to fulfill ACA data collection requirements and an IT business operations plan for ACA compliance. The new application for the Affordable Insurance Exchange Establishment grant through HHS will further expand the NM Exchange IT systems and data collection requirements. Development of these systems will need to follow the ACA minimum functions of the Exchange.

A state should develop sound data and analytic methods to drive decision-making about their Exchange and will need sufficient quantitative and qualitative information to monitor and evaluate exchange implementation.

Despite ACA mandates there are many choices for states as they design and implement exchanges. For example, how will the Exchange be financial stable, will there be a regional Exchange, what is the role in individual and small group markets, and how will data collection and IT infrastructure best be constructed to meet state policy goals? States can also go beyond the requirements of the ACA and define their Exchange policy priorities that will best meet their individual state needs. For instance, Washington State plans to develop an evaluation template to ensure that data collection systems are in place for tracking the impact of their Health Insurance Partnership and future reform efforts. (State Health Access Assistance Center. “Health Insurance Exchanges: Implementation and Data Considerations for States and Existing Models for Comparison. “ October 2010.)

States also have the opportunity, at the exchange design stage, to create the data infrastructure needed to support program implementation and revision as well as to meet the information demands of state and federal policy makers.

— State Health Access Assistance Center (SHDAC).
In its application and proposal for the “Establishment Grant of State-Operated Health Insurance Exchanges” the State of New Mexico must address the following key IT functions:

1. Eligibility  
2. Enrollment  
3. Premium tax credits administration  
4. Cost-sharing assistance administration  
5. Health plan management to support Qualified Health Plan certification  
6. Payment management system for Free Choice Vouchers

Six states and a multi-state consortium have received over $241 million from DHHS in Early Innovator grants to develop model Affordable Insurance Exchange IT systems. All Early Innovator states committed to assuring the technology developed is reusable and transferable. The six Early Innovator states will provide models for how Exchange IT systems can be created.

Affordable Insurance Exchange Establishment grants help states continue their work to implement this key provision of the Affordable Care Act. The grants recognize that states are making progress toward establishing Exchanges but are doing so at different paces. Of the seventeen states receiving the Level One of $185 million of Exchange Establishment grants fourteen have specific detailed plans to utilize all or a portion of the funding to strengthen the health information technology systems that will be integral to the Exchange. The other three states will utilize some funding for data and IT systems evaluations. The fourteen states will also look to support the information, data and IT policy options for full implementation of the Exchange; conduct a thorough analysis of information technology capabilities; design the business requirements and IT detailed design, implementation of the Exchange IT platform, including product licensing, system integration, and independent verification and validation; and build the exchange IT system to coordinate with state agencies to enable a streamlined, single-portal eligibility and enrollment system.

The ACA ensures that there are core IT elements and that the Exchange IT systems for every state are comprehensive and reusable by other states. Systems must be interoperable and integrated with state Medicaid and Children’s Health Insurance Program (CHIP) programs and be able to interface with HHS and other federal data sources in order to verify and acquire data as needed.
An issue that’s not often discussed is whether aspects of the data system that consumers can access are realistically "accessible" to persons with disabilities. Will there be, for example, data collection and web-site systems under which consumers with disabilities can without much difficulty apply on line for benefits? Assistive technologies should be a planned and designed element in the Exchange. These may include training and support, physical infrastructure accommodations, and conversion of Exchange information and materials into accessible format such as Braille and screen readable text, adaptive computers and other technology-based disability accommodations. In a study supported by the National Center for Legal and Economic Justice (NCLEJ), a team of law students from the Northeastern University School of Law tested the accessibility and usability of public benefits agency web sites in California, Florida, Michigan, New York, and Texas. (LaCheen, Cary. “The Closed Digital Door: State Public Benefits Agencies’ Failure to Make Websites Accessible to People With Disabilities and Usable for Everyone.” The National Center for Law and Economic Justice. June 22, 2010.)

Some Web accessibility problems for people with disabilities in the study were documented as:

▷ Accessibility problems that prevent application for benefits online.
▷ Accessibility problems that prevent individuals from contacting the agency for an application or for information.
▷ Accessibility problems that prevent a search on the agency’s web site.
▷ Inadequate color contrast that makes it difficult for individuals with low vision to read.
▷ Design choices that make it difficult or impossible for individuals using assistive technology to read.
▷ Missing text labels for pictures, tables, search boxes, and other non-text elements. They could not be read by individuals with disabilities using screen readers.

The state Exchange IT systems and infrastructure should address these accessibility needs early on for disabled individuals.
dispari•ty

pronunciation: [dih-spar-i-tee]
noun
1. The condition or fact of being unequal, as in age, rank, or degree, difference: Narrow the economic disparities among regions and industries.
2. Unlikeness, incongruity
Effective use of data at the state level can support the establishment of health care quality indicators and outcome measurements for the population at large, and in particular vulnerable children, families and communities. Moreover, linking federal, state and local data sources to address health disparities for vulnerable populations should be a major planning and design factor as the state moves toward ACA implementation and develops its Exchange criteria.

Across the country, there are efforts based in States and regional collaboratives that are at the cutting edge of measuring quality performance outcomes. There is no need for any state to start from scratch when advancing quality outcomes or addressing health disparities and collecting data to support reporting and measurement of quality or health disparities indicators. A myriad of federal resources as well as New Mexico health care reports have been produced over the last several decades to design and put into practice health quality indicators and measures and define how to undertake progress on the elimination of health disparities. The big effort for New Mexico will be to aggregate these resources, refine them into usable data functions for the state, and make them available for public consumption and easy understanding.

The NM Department of Health (DOH) annual report, *The State of Health in New Mexico 2011* provides NM health trends from 1998 – 2009, a decade of data collection and analysis that is organized by health care indicators. The document sets out declining trends and worsening trends and challenges to be met to reverse worsening health indicators. The report is easy to read and uses graphics to easily illustrate data. The NM DOH also initiated in 2006 a “Racial and Ethnic Health Disparities Report Card” that has been updated each year, with August 2010 the 5th edition of the report. The report uses major NM sources of federal and state data to aggregate its findings. As noted by the DOH, it is “efforts to improve the health of all racial and ethnic groups in key areas such as infectious disease, substance abuse, maternal and child health and chronic disease. Indicators in the report card reflect areas in which New Mexico’s rates are higher than the national rate (suicide) or areas with
large disparities between populations (infant mortality) or both (teen births).” The health disparities report is an example of how NM has begun to analyze health indicators and disparities utilizing multiple sources of data. The critical strategy for the state is to begin to electronically develop these data sources of quality and health disparities indicators for governmental as well as public use and transparency of information. As health reform IT design and implementation progresses in the state, it will need to develop more sophisticated IT tools for reporting, creating networks to federal databases, aggregating data from other state and local agencies and providing consumer transparency in the operation of the Exchange, health insurance pricing and other financial control areas.

Preparing for implementation of the ACA presents the State with a unique opportunity to reconnect with public health and behavioral health collaborative and local government health quality initiatives around the State. For example, Doña Ana County Health and Human Services Alliance has their Action Plan Update (April 1, 2009) and continues to working a collaborative county effort with nongovernmental organizations, the university, community representatives and other groups to continue to build on health indicators and priority quality health outcomes and disparities reduction goals. Likewise, McKinley and San Juan County representatives from the former community health councils have joined a statewide collaboration process with other county councils and behavioral health collaboratives to update their health action plans. Bernalillo County has also commenced its update looking at priorities that include social indicators of health such as a living wage, health and educational outcomes for children and youth from pregnancy to age 25, and Improve access and quality of care for indigent and uninsured population.

A big challenge was presented when the county health councils were defunded in the 2011 fiscal year and many are unable to continue their productive public health and health services efforts. Despite this setback, there is a continuation by the majority of health councils to continue their local work through a “NM Alliance of Health Councils.” The defunding was unfortunate, since the county health councils have been community oriented where participants in the Action Plans were encouraged to consider health care reform implementation within the context of community health needs and priorities. Community representatives during the statewide Alliance undertaking to update statewide health plans have reviewed the priorities for each of the community health councils around the state and learned about several community-based strategies designed to improve health outcomes for children and families. Now is a good time for the state to support these local efforts and connect them to statewide health care reform design and implementation.

Federal sources are rich with quality outcomes and health disparities reporting, data collection, surveys, research and national priorities. The information is compiled electronically, much of which is available to states which can link into the sources of information directly, displaying data that includes major navigation points allowing users to access measures and information in a variety of ways. For example, the Health Indicators Warehouse (National Center for Health Statistics) provides quick access to a full health measures while also providing links to other points of interest. Health metrics can be searched by topic, geography, and health indicator initiative. In addition, the web page tab can be used as an interactive tool to get to specific health indicator estimates.
There are several federal survey data instruments that can be very useful to the State of NM, local governmental agencies, community organizations dealing with health care and local health care collaborative. Familiarity with these data sources can be a primary baseline for the state to interface data between its sources and federal data and local initiatives in order to meet ACA requirements and provide transparency to consumers and all stakeholders.

One of the best resources available to states and other groups is the State Health Access Data Assistance Center (SHADAC). The State of NM has developed a relationship through their RWJF grant for ACA implementation. This assistance should help the State in its progress toward full ACA implementation of the Exchange and other health reform infrastructure functions. SHADAC has compiled information for use by states and others that outlines various federal data survey resources that will assist in monitoring impacts of health care reform, health care access, insurance coverage and health disparities and other reform sectors. Major federal data survey assets include:

- American Community Survey (ACS)
- Current Population Survey (CPS)
- National Health Interview Survey (NHIS)
- Medical Expenditure Panel Survey–Household Component (MEPS-HC)
- Behavioral Risk Factor Surveillance System (BRFSS)
- National Survey of Children’s Health (NSCH)
- Survey of Income and Program Participation (SIPP)

In its report to Congress, DHHS set out its National Strategy for Quality Improvement in Health Care, which will pursue three broad goals to guide and assess local, State, and national efforts to improve the quality of health care.

**Better Care**
Improve overall quality by patient-centered, reliable, accessible, and safe care.

**Healthy People & Communities**
Support proven interventions to address behavioral, social and, environmental determinants of health in addition to delivering higher-quality care.

**Affordable Care**
Reduce the cost of quality health care for individuals, families, employers, and government.
The National Quality Strategy is designed with stakeholder input and from around the nation to measure and improve health and health care quality, align all stakeholders for quality, keep performance data on line to inform consumer decisions, and add hospital pricing information. DHHS will also develop national consensus on specific measures, data sources, and data collection procedures which will be useful to state agencies, community health organizations and consumers generally. (DHHS Report to Congress: National Strategy for Quality Improvement in Health Care, March 2011.) DHHS will establish data on care delivery and outcomes using consistent, nationally-endorsed measures and will help coordinate quality measurement efforts. Efforts will focus on aligning measurement efforts within value-based purchasing programs and move to measuring outcomes and patient experience.

Building a Quality Care and Data Transparency Foundation to Eliminate Health Disparities

It is well documented that racial and ethnic as well as geographic, environmental and other social status indicators point to an unsustainable path to increasing health disparities in the health care delivery system. These health disparities are particularly inherent in racial and ethnic minority groups. Collecting and analyzing valid and reliable data regarding racial and ethnic health disparities provides the foundation for identifying differences in care and developing targeted interventions to improve the quality of care delivered to vulnerable population groups. (Economic Burden of Health Inequalities in the United States: http://bit.ly/wmMoa)

According to a recent study by the Joint Center for Political and Economic studies, eliminating health disparities for minorities would have reduced direct medical care expenditures by $229.4 billion between 2003 and 2006. And not surprisingly, research and studies have documented that establishing, implementing, and monitoring quality outcomes through various health indicators for vulnerable populations over the long term will significantly reduce health disparities. Thomas A. LaVeist, Darrell J. Gaskin, Patrick Richard, "The Economic Burden of Health Inequalities in the United States," (The Joint Center for Political and Economic Studies: September 2009).

States have shown increased interest in documenting health disparities over the last two decades utilizing a variety of methodologies to collect, aggregate and report the data. By documenting populations with poor health outcomes the state can target quality interventions and better utilize its resources to get increased value for its expenditures thereby containing costs. With the rising costs of health care in all sectors, eliminating health disparities will provide efficiencies in the state budget overall and enhance cost containment measures throughout the health delivery system in the public and private sectors.

DHHS has reaffirmed its commitment to eliminating ethnic and racial health disparities through a number of new initiatives informed by the ACA. Included in these initiatives is implementing the goals of Healthy People 2020 wherein one of the four overarching goals is “to achieve health equity, eliminate disparities and improve the health of all groups.” This initiative will assess health disparities in the U.S. population by tracking rates of death, chronic and acute diseases, injuries, and other health-related behaviors for populations defined by race, ethnicity, gender identity, sexual orientation, disability status or special health care needs, and geographic location. (DHHS, Office of Disease Prevention and Health Promotion, Healthy People 2020; www.healthypeople.gov.)
Data used by states to track and attend to reductions in health disparities should conform to federal data collection efforts with interoperability capabilities between state IT and federal databases. Local data collection efforts at the county and state levels should feed federal efforts. Data should be put in the public domain for public consumption, review and use in making health care delivery improvements and insurance coverage reforms.

The HHS Action Plan to Reduce Racial and Ethnic Health Disparities, following the mandates of the ACA, seeks to ensure that data collection standards for race, ethnicity, sex, primary language, and disability status are implemented throughout HHS and other federally supported programs, activities, and surveys. (DHHS. “Action Plan to Reduce Racial and Ethnic Health Disparities: A Nation Free of Disparities in Health and Health Care.” April 2011.) The Action Plan will:

- Ensure public access to data to promote disparities research
- Assure that data on race and ethnicity in federally supported programs, activities, or surveys is routinely reported in a publicly available format
- Use data to map and accelerate comprehensive planning to coordinate local disparities reduction activities
- Develop a system of public reporting of preventable hospital admissions by race and ethnicity
- Publicly display aggregately collected Medicaid and Medicare quality measurement data in new ways that call attention to racial and ethnic disparities.

Section 4302 (Understanding health disparities; data collection and analysis) of the ACA amends the Public Health Service Act to expand the current requirements for the collection and analysis of health disparities data. All federally funded health programs and population surveys will be required by 2013 to collect and report data on race, ethnicity, primary language, and other indicators of disparity. This provision strengthens data collecting and reporting mechanisms in Medicaid and the Children’s Health Insurance Program, bringing them up to the same standards as Medicare.
Racial and ethnic data on commercially insured enrollees are not typically available from purchasers such as employers, so health plans must collect their own data. Incentives are particularly needed to encourage health insurance plans to collect data on racial and ethnic disparities and to do this to agreed standards and methodologies so that the data can be used to address disparities and, ideally, shared with government and researchers. The development of these standards and methodologies should involve the relevant community stakeholders. Center for American Progress. “Measuring the Gaps: Collecting Data to Drive Improvements in Health Care Disparities.”

—Lesley Russell. December 2010

Because all this information and data can be overwhelming, now is the time for the State of New Mexico to renew its commitment to collaborative efforts to aggregate data for quality outcome indicators, track efforts to eliminate health disparities and provide transparency to the public. With a variety of data collection systems operating it will be critical to ensure that there are sufficient common standards and uniformity in how the data is collected to enable the sharing of data across federal, state and local agencies.
**transparent**

pronunciation: [trans-pair-uhnt]

*adjective*

1. a (1): having the property of transmitting light without appreciable scattering so that bodies lying beyond are seen clearly, PELLUCID. a (2): allowing the passage of a specified form of radiation (as X-rays or ultraviolet light). b: fine or sheer enough to be seen through, DIAPHANOUS.
2. a: free from pretense or deceit, FRANK. b: easily detected or seen through, OBVIOUS. c: readily understood. d: characterized by visibility or accessibility of information especially concerning business practices.
Collecting Data: What do we do with it?

- Show It Off
- Share It
- Use It
Opportunities for New Mexico

Management - The Interagency Collaboration (NM Health Reform Leadership Team)

New Mexico continues its Health Reform Leadership Team established after the passage of the ACA. To its credit the group has monitored ACA activities, moved to take advantage of funding and grants from federal agencies and philanthropy. The Leadership Team has provided for stakeholder input and developed some outreach strategies through contractors and agency representatives.

The State now has the opportunity with its Leadership Team to expand its consumer and provider outreach through establishing foundational principles on data collection and transparency and the relationship to the design and implementation of the Exchange. The State can use its work on its human services IT GAP analysis to plow new ground on data transparency and communicate how it will address quality measurement data in new ways that call attention to racial and ethnic disparities.

Transparency

Openness is a critical factor to achieving transparency in health care reform implementation. It is an attitude of the governmental organization which allows its functions to be readily accessible to the public. It is a willingness to be forthright with the public’s trust. Health care reform provides the state and consumers the ability to build a trust relationship leading to quality health care for all.

Develop transparency and data guidelines and working principles for use across sectors and in particular for implementation and operation of the HIE. Collaborate with current stakeholders and seek broader perspectives from local communities. Data from HIE and other health reform activities should be transparent, easily available for review, and set out in multiple sources of consumption.

Don't Reinvent the Wheel/BUILD on What Has Been Started

New Mexico and federal agencies have developed quality indicators to improve health outcomes of its populations including health disparities in racial and ethnic minorities. Similarly as with its IT GAP analysis the State can also promulgate a GAP analysis current data on health outcome indicators from counties, community health centers, local governments, and county health collaboratives.

Designing for the ACA also provides a unique opportunity for the State to utilize the expertise of local communities which understand what happens on the ground between the health care delivery system and consumers in their communities. Organizations and consumers in local communities have developed strong data collection points and interact on a daily basis with people and providers.
Opportunities for New Mexico (continued)

Utilize Current County & Community Data/Keep It Current

There should be a commitment to take current locally collected county and community data and include indicators of racial and ethnic health disparities at a community level and continue updates to make this data relevant and current.

One of the best methods to interface at an on the ground level and keep data relevant is through community based participatory research. While this requires some training of community and workers on the ground many New Mexico counties and health collaborative know and understand this participatory research concept. Once established, it can be key to design and implementation of major provisions of the ACA. When given the opportunity, most community health providers and leaders will embrace the chance to establish a relationship that makes their health care challenges relevant to policy makers. Community based participatory research allows communities to share their knowledge and experiences and share their historical social, environmental and health outcomes data and information collected over the decades.

Elimination of Health Disparities

New Mexico has its “Racial and Ethnic Health Disparities Report Card” which has been a good start to documenting New Mexico issues and establishing some indicators for addressing health disparities. The Report Card does not transcend to higher plane of ACA planning, such as how health disparities can be focused on in Exchange operations. Having a commitment to lowering health disparities requires setting up a time frame to implement strategies to eliminate them, utilizing data from the Exchange, tapping into federal data collection tools, and creating new aggregated state data tools for determinants of health.

Some states conduct their own population health disparities surveys, which tend to have more in-depth information about health indicators and disparities outcomes. They may include such indicators as health insurance coverage and related issues such as health status and use of services. The ACA provides a backdrop to begin a health disparities population survey in New Mexico and it can also be a promising source of data for modeling the impact of policy changes for eliminating racial and ethnic health disparities.

All this is not easy and necessitates a commitment to long-term work on reduction and elimination of health disparities. Those working in health care reform should acknowledge these difficulties and deconstruct the work so that this goal does not feel unbearable and unachievable.
Opportunities for New Mexico (continued)

Acknowledge Social and Environmental Determinants of Health are Real

As with quality indicators and outcomes, many states and federal agencies have developed criteria of social and environmental determinants of health. Looking at the NM county health collaborative work plans over the last decade, it is clear that social determinants are a big part of each plan and discussion of the health of various communities around the state. The NM DOH also in its presentation of “Health Status in New Mexico 2011” has identified social indicators of health, although the agency does not acknowledge them as such. For example, annual income, self reported health status by educational breakdown, binge drinking by education and income, risk behaviors by family relationships.

Other social determinants will track the health needs and quality outcomes for disabled populations. For instance, community accessibility including transportation to and from health providers and home health care, where there is a continuing lack of public transit in all geographic areas of the state, particularly in rural communities.

The next logical step can be to acknowledge, identify and set standards and metrics for social and environmental determinants of health within the context of vulnerable communities, families and children.

It is a matter of building on what has already been started.

Track the Impacts of the ACA in New Mexico

Commencing this evaluation process during early design of the Exchange and planning for ACA implementation generally is critical to affecting quality outcomes, eliminating health disparities and presenting data in a transparent and thoughtful way to policymakers and the public about the impacts of health reform.

A structured data and evaluation strategy can compile meaningful information and highlight key quality outcome measures and make technical documentation accessible and transparent.

New Mexico has some unique opportunities to work with current philanthropic endeavors in the State that will bring together stakeholders from distinct and diverse backgrounds and communities. These stakeholder networks can build an evaluation and data collection assessment of ACA impacts on health care delivery strategies and health care reform requirements.
Department of Health and Human Services (DHHS). “Notice of Availability of Proposed Data Collection Standards for Race, Ethnicity, Primary Language, Sex, and Disability Status Required by Section 4302 of the Affordable Care Act.” Federal Register / Vol. 76, No. 126 / Thursday, June 30, 2011 / Notices


National Academy for State Health Policy. www.statereforum.org/taxonomy


References


Russell, Lesley. “Measuring the Gaps: Collecting Data to Drive Improvements in Health Care Disparities.” Center for American Progress. December 2010
