

Maternal and Child Health Measurement Research Network (MCH-MRN) Strategic Agenda

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CAHMI
The Child & Adolescent Health Measurement Initiative

Johns Hopkins Bloomberg School of Public Health | Population, Family and Reproductive Health

Coordinated by CAHMI
MCH-MRN
Maternal & Child Health Measurement Research Network

Introduction

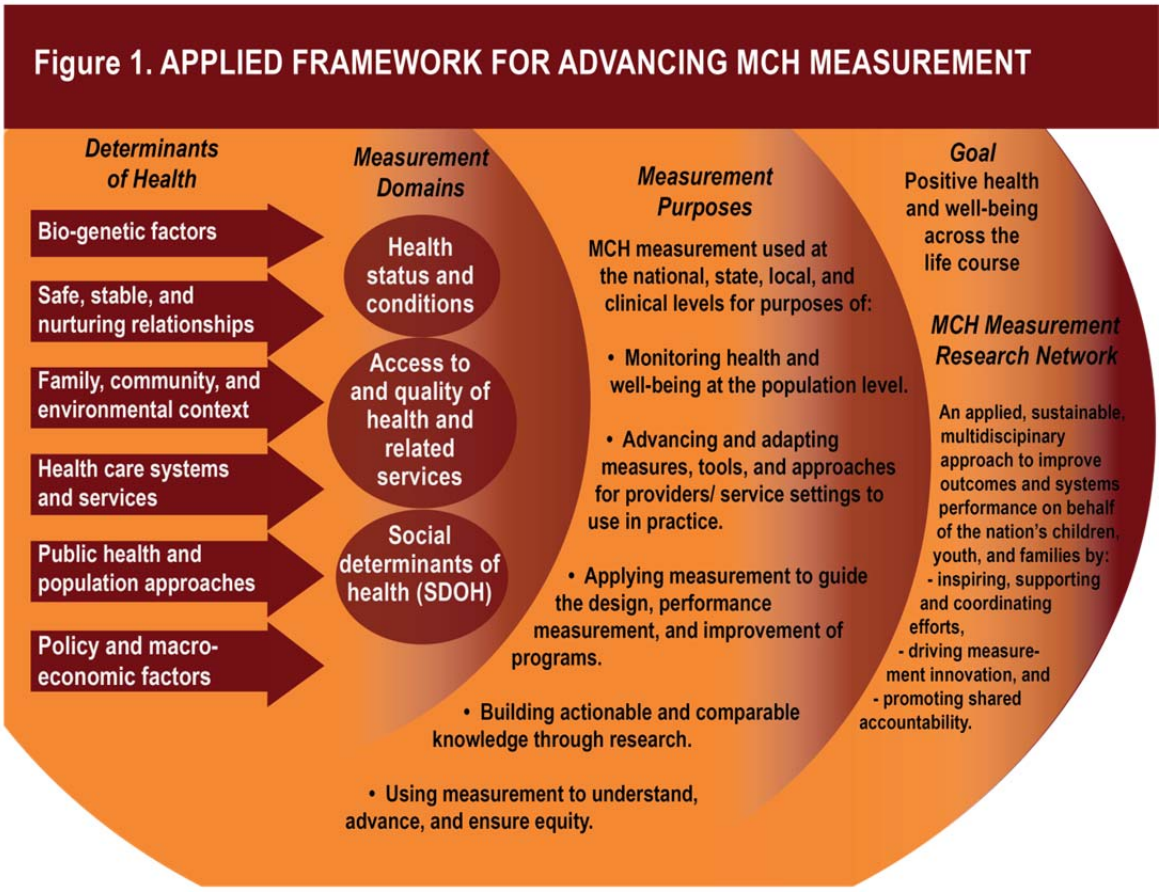
The Maternal and Child Health Measurement Research Network (MCH-MRN) is a multidisciplinary, collaborative network of experts who represent the MCH lifespan and who are active in the measurement of health and well-being of MCH populations. The MCH-MRN is sponsored by the U.S. Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB) (UA6MC30375). The 2016-2019 cycle of the MCH-MRN is led by the Child and Adolescent Health Measurement Initiative (CAHMI).

The purpose of the MCH-MRN is to provide a sustainable platform to inspire, support, coordinate, and advance efforts related to MCH measurement, measurement innovation, and shared accountability to improve outcomes and systems performance on behalf of the nation's children, youth, and families. This robust and broad-based Network—grounded in a common framework, shared vision, and Strategic Agenda—is designed to improve, align, and harmonize measures and data across the diverse landscape of systems, programs, and practice settings responsible for promoting and protecting the health and well-being of MCH populations.

From Fall 2016 to Summer 2019, the MCH-MRN aspires to establish and maintain:

- **A common, recognizable framework,** which reflects a shared vision for measurement domains and applications essential to promoting the health and well-being of women, children, youth and families across the life course.
- **A Strategic Agenda embraced by MCH stakeholders,** which leverages existing opportunities and addresses key gaps to ensure innovative and effective MCH measurement, and guides the development and harmonization of measures across programs and initiatives where doing so adds value.
- **An applied network,** which provides the platform and opportunities for interdisciplinary experts who represent the MCH lifespan to connect and develop innovative MCH measurement initiatives.
- **Actionable resources**, which support MCH stakeholders in their knowledge and use of MCH measures in priority areas, and the development and application of measures into a variety of practices, policies, and processes.

The MCH-MRN is responsible for setting a national strategic agenda for MCH measurement research. This document describes the strategic agenda, how it was created, and what it aims to achieve.



What is the focus of the Strategic Agenda for MCH measurement?

The MCH-MRN Strategic Agenda:

- Aims to improve MCH measurement and its application toward better health and well-being for MCH populations;
- Is based on identified gaps and opportunities in MCH measurement;
- Makes recommendations for action to fill gaps and optimize opportunities;
- Sets short-term priorities for action in research, capacity building, and other areas;
- Promotes the development, harmonization, and alignment of measures across programs and initiatives; and
- Guides translation of knowledge and data using MCH measures into policy, programs, and practice.

The MCH-MRN and its Strategic Agenda are grounded in a growing understanding of the science of human development, which creates unprecedented opportunities to advance human health and well-being. This work is likewise based on the World Health Organization definition of health as a state of complete physical, mental, and social well-being, not merely the absence of disease or disability. Existing science provides evidence that the determinants of health categories listed in Figure 1 are multi-factorial, interrelated, emergent, and largely malleable. In

the MRN framework, these determinants range from bio-genetic factors to relationships and family and community context to health services to policy and macro-economic factors and are placed into three broadly defined MCH-MRN measurement areas, each of which are anchored to the goal of promoting early and lifelong health and well-being. The three areas are health status and conditions, access to and quality of health and related services, and social determinants of health. The framework recognizes the importance of factors beyond health care services as fundamental for changing health and well-being at the individual and population levels; and the need for cross-sector collaboration and integration at the policy, program and policy levels.

In light of this broad-based understanding of health and its determinants and the goal of MCH measurement to promote positive health and well-being across the life course, the priority purposes for MCH measurement summarized in Figure 1 include: (1) monitoring health and well-being at the population level, (2) advancing and adapting measures, tools, and approaches for providers/service settings to use in practice, (3) applying measurement to guide the design, performance measurement, and improvement of programs, and (4) building actionable and comparable knowledge through research, and (5) using measurement to understand, advance, and ensure equity.

The MCH-MRN Strategic Agenda especially points to key opportunities and gaps to promote effective and harmonized MCH measurement across programs and initiatives, many of which are or need to collaborate at the national, state, or local levels. The Strategic Agenda also seeks to respond to current needs and opportunities to inform and guide programs, policy, and practice through improved measurement practices

While many measures exist, policy and program leaders and practitioners at all levels are still faced with:

(1) Critical gaps in availability of important measures of health, particularly measures of positive health and its determinants, rather than just the existence or absence of risks, illness, and injury;
(2) Unnecessary variation and lack of alignment and harmonization among measures within and across programs and service settings that limit shared accountability and collaboration; and
(3) Barriers in access to information about, micro-data for, scientific validity and value of, and support to effectively use and learn from existing MCH measures

These and other factors lead to gaps in knowledge and limit data available to guide and track the impact of actions and change. These factors also contribute to redundant, fragmented, non-comparable data across MCH agencies and programs. There have been increasing calls to action to foster sustainable and standardized MCH measurement systems, like the Title V National Outcome Measures and National Performance Measures and Healthy People 2020. Such systems are critical to guide program design and implementation, drive and demonstrate accountability, and continuously improve outcomes and performance. A scan was done of existing measures required or embraced by existing key MCH programs and initiatives in the US that have formally incorporated measurement into their reporting and work. Doing so was the first step to ensure the MCH-MRN strategic agenda is anchored to a review of existing MCH measures in use and then to identify alignment opportunities and gaps. This scan was central to the development of the Strategic Agenda to improve MCH measurement. Methods used to develop the Strategic Agenda are further outlined below.

How was the Strategic Agenda developed?

Agenda building is the process through which strategic issues are legitimated in an organization and gain attention from decision makers. The strategic agenda of an organization is the set of issues that consume the attention of leaders and guide resource allocation. Strategic agendas are often built through collective or group actions, generally by using communications, issue development, and consensus building. Champions, entrepreneurs, and opinion leaders play a key role. The process for developing the Strategic Agenda for MCH measurement used all of these approaches.

In 2013-2016, the CAHMI led a four-part stakeholder input process and four step environmental scan of existing MCH measures to lay the foundation a Strategic Agenda for MCH measurement to guide the MCH-MRN. First, a broad range of nearly 400 stakeholders (n=388) were engaged to identify, further specify, and prioritize MCH measurement gaps and opportunities using four methods: (1) key informant interviews, (2) input forms on priorities, gaps, and needs completed by participants attending a range of national meetings and through email based solicitation of MCH stakeholders, (3) listening sessions and engagement with related efforts in the field and (4) in-person meetings with MRN advisors and partners.

Second, beginning with a review of the 12 MCH programs recommended for review during the input processes outlined above, the CAHMI developed a four-part MCH measurement review process. This process entailed identification of programs to include, procurement of measurement documentation, development of a review template and characterization of measures, classification of measures, and an across set and measures synthesis of MCH measures used in these 12 programs. Simultaneously, the online searchable compendium was created. See box below for a list of the 11 programs and initiatives the CAHMI ended up including in this scan. Measures in use with Head Start were not identified and the scan for this program ended at the "procurement of measurement documentation" phase of the process since no standardized measures are uniformly used or reported in this program.

The review identified more than 800 measures that address over 200 topics, with fewer than 15 shared measurement topics across the 11 programs and systems. A searchable, web-based compendium of measures was developed to make this new resource accessible to the MCH field (http://childhealthdata.org/browse/mchmeasurement). This environmental scan identified critical gaps in the availability of measures to understand and promote improvements in the health and well-being of children and families in the United States. Together, the stakeholder input processes and the four-part MCH measurement review process resulted in the identification of eight different types of MCH measure gaps and opportunities that inform the Strategic Agenda. This, in turn, led to identification of opportunities for short-term action and change.

MCH Programs and Initiatives Scanned for the MCH-MRN Strategic Agenda

1. AMCHP Life Course Indicators
2. Child Welfare (Title IV) Outcome Measures
3. National Committee for Quality Assurance's Healthcare Effectiveness Data and Information Set (HEDIS)
4. Healthy People 2020 Indicators
5. Maternal, Infant, and Early Childhood Home Visiting (MIECHV) Program Performance Measures
6. Medicaid/Children's Health Insurance Program (CHIP) Core Child Measures Set
7. National Quality Forum
8. CMS Pediatric Quality Measurement Program (PQMP) Measures
9. NIH Patient Reported Outcomes Measurement Information System (PROMIS) Measures
10. Title V Block Grant (post-2015) National Performance and Outcome Measures (NPMs and NOMs)
11. Title V Block Grant (pre-2015) NPMs and NOMs

Synthesis of Key Stakeholder Input Processes

Phase one of the environmental scan on MCH measurement collected qualitative data from 29 in-depth interviews with key informants who possess expertise in MCH measurement research, policy, and practice. Additional data was collected via an input tool on MCH measurement priorities, assets, gaps, and need using online and in person meeting methods to engage stakeholders. Listening sessions with state and local MCH health leaders through participation in meetings held by these leaders or through discussions held at annual meetings and conferences were essential as well. The listening sessions occurred in structured and unstructured opportunistic processes with stakeholders who attended the annual meetings of the Association of Maternal and Child Health Programs, MCH Epidemiology/CityMatCH, American Public Health Association, Pediatric Academic Societies and AcademyHealth as well as with other recommended affiliates of the CAHMI and the MCH-MRN advisory board (n=388).

Data obtained through the key informant interviews, listening sessions, and in person meetings were transcribed, analyzed, and the results summarized. The data obtained through the MCH MRN input tool was similarly analyzed and summarized. Themes included the need for: use of measures to show effectiveness, coordinate national, state, and local standards, and drive quality improvement; improvement in local data and coordination and linking across sectors and organizations; and action to fill key content area gaps reflected in the recommendations set forth in this Strategic Agenda. These findings helped to frame further environmental scan efforts and recommendations in three main ways: (1) identification of existing measurement frameworks to review, (2) identification of programs and initiatives to review for their formal use of MCH measures, and (3) the development of the four-step MCH measurement review strategy summarized above and described more below that resulted in the online, searchable MCH Measurement Compendium.

Measurement Review Process

As noted, this process included:

- Identification, procurement, and review of documentation from measure sets officially used by the MCH programs/initiatives recommended for the measurement scan by stakeholders;
- Development of a model for characterizing measures;

- Characterization of individual measures in each set across multiple aspects of measurement (see below). CAHMI's characterization of the measures and measurement set was reviewed and verified by measurement set developers/sponsors;
- Classification of measures identified into high level and subtopic areas aligned with the MCH MRN measurement framework; and
- Synthesis and summary of MCH measures identified
- Documentation and organization of MCH measures into a searchable, online measurement compendium.

Once completed, findings were used to summarize measures by topic, settings, and other factors and to identify gaps and opportunities in consideration of priority domains, purposes, and goals for MCH measurement set forth in the framework.

Further detail on the review process and high level findings is summarized below.

Measure Review Part 1:

As noted, 11 MCH programs that officially use or set forth a specific set of measures (listed above) were identified and a model for characterizing the measurement sets and individual measures specifications was created based on the review. The parameters for characterizing measurement sets were: (1) primary purpose, (2) reporting requirements, (3) units of analysis/settings for measurement, (4) range of topical areas addressed, (5) range of target populations addressed, (6) availability of development, technical, and validity specifications for the set, (7) availability of micro-data findings, (8) range of data sources required, and (9) types of recommended or required stratifications for measures included in the set in order to address health equity, disparities, and other variations by important subgroups.

Measure Review Part 2:

As a next step, the 800+ measures in the 11 measure sets were characterized according to specific parameters and entered into a data base developed to support a measurement set and measure query searchable query tool. Parameters for characterizing each individual measure in these 11 sets included: 1) specific data source required to produce the measure, (2) specific target population, (3) detailed topic addressed (more than 200 specific topics were identified), (4) specific sampling unit of analysis, and (5) whether this measure or topic was also included in another programs/initiative for which measures were reviewed.

Measure Review Part 3:

Next, each measure was further categorized into higher level categories aligned with the MCH-MRN framework. The topical categorization scheme was simplified in 2018 based on input from stakeholders. This simplified scheme organizes measures into three areas: 1) health status, well-being, and health conditions across the life course, 2) access and quality of health care services, 3) social determinants of health. (See Figure 2.) A final comprehensive classification scheme organized measures by these three domains. 13 high-level and more than 70 measure subtopic areas were developed across these three domains to summarize measures identified.

Figure 2. MCH-MRN Measurement Compendium Three Core Areas and High-Level Topics

Goal: Positive health and well-being for women, infants, children, adolescents, and their families.

Health status, well-being, and health conditions across the life course

Overall Health and Well-being

- Positive health and life satisfaction
- Social-emotional well-being
- Developmental trajetory

Condition Prevalence

- Physical conditions
- Pregnancy, perinatal, birth and sexual health conditions
- Mental, relational, emotional and behavioral health conditions
- Oral health conditions
- Children with special health care needs (CSHCN)
- Infectious disease
- Non-fatal injuries

Health Protective and Risk Behaviors

- e.g., physical activity, injury prevention, sexual health behaviors, drug and alcohol use

Mortality

Access to and quality of health and related services

Health Coverage and Access to Care

- Access to health professionals and facilities
- Access to services and supplies
- Health insurance coverage
- Economic access and affordability

Health Service Utilization

- Screening for prevention and early detection
- Preventive care, visits, and immunizatoin
- Diagnosis and treatment services, including hospitals
- Mental, relational, emotional and behavioral health services
- Utilization of related services (e.g., nutrition, early intervention)

Health Care Quality

- Medical home and systems of care
- Appropriateness of care process
- Patient experiences (satisfaction, medical errors)

Social determinants of health (SDOH)

Social Determinants of Health

- Economic factors (e.g., income, employment, food security)
- Familiy and community context (e.g., abuse, safety, peer relation-ships, social cohesion)
- Equity and racism (e.g., perceived discrimination, neighborhood segregation)
- Education (e.g., parental education, school attendance, graduation)
- Physical and built environment (e.g., access to healthy foods, crime and violence, environmental exposures)
- Policies and programs (e.g., health, justice, or housing policy)

Measure Review Step 4:

Measurement assets, gaps, and opportunities, as well as overlap in topical areas and specific measures used across MCH programs/initiatives were identified by examining and synthesizing information obtained from the review activities outlined in measure review steps 1-3. Information gained during the stakeholder review steps outlined above and based on the MCH-MRN framework guided the strategic review of measures and the identification of gaps and opportunities. Findings are outlined below.

What gaps and opportunities were identified?

Amid the substantial MCH measures identified, critical gaps to ensure comprehensive and effective use of measures emerged. Specifically, eight different types of MCH measurement gaps and opportunities stood out, which are summarized here.

Conceptual gaps and opportunities

Despite the impressive range of topics of MCH measures used in existing MCH programs and initiatives reviewed, the majority of MCH measures applied in these efforts assess access to or receipt of services (37%) and social and behavioral determinants (35%). Few measures focus on positive health outcomes and well-being. This suggests that the US has not fully embraced all dimensions of health as well-being through physical, mental, and social health. Most notable conceptual gaps were found in the following areas: 1) well-being and life satisfaction; 2) positive health; 3) socio-emotional development and functioning; 4) family health and relationship factors; 5) measures for early and middle childhood; 6) perinatal health, and 7) life transitions.

Population-based gaps and opportunities

Measures exist that could be of relevance if applied to additional MCH populations. Of particular note was the absence of key measures for youth, likely due to the need for youth reported information, which involves the support of data collection methods allowing for youth report. Also, many measures are a part of data collection systems that do not allow stratification by race/ethnicity and other key variables needed to inform action. For example, teen pregnancy measures exist but in systems that limit analysis of variations or factors explaining variations.

Use gaps and opportunities

Many measures identified in the review are underutilized and, if used, might fill critical gaps. For instance, while HRSA/MCHB's Title V National Outcome and Performance Measures are highly relevant for all populations, they are targeted for use only by Title V agencies. In addition, the CMS Pediatric Quality Measurement Project (PQMP) has more than 80 measures, yet at the time of our review only one had been incorporated into the Medicaid/CHIP Child Core Set or other measurement sets. Many measures from the CDC's Healthy People 2020 and the NIH-PROMIS measurement sets remain similarly underutilized in the MCH field. In addition, there is potential to advance harmonization of measures across programs. A broader review of sources of data for MCH measures in the field points to an underutilization of data from the National Health Interview Survey, the Youth Risk Behavior Surveillance System, the Behavioral Risk Factor Surveillance System, the Pregnancy Risk Assessment Monitoring System (PRAMS), and the Medical Expenditure Panel Survey (MEPS). Information from these and other national surveys and surveillance systems can assist MCH programs in measurement for additional topic areas (e.g. hospitalization, health status, missed school, family factors, pregnancy experiences). Many

of the NQF endorsed measures are not widely used and other issues related to sustaining NQF endorsement were noted that have led to the elimination of many MCH measures whose validity properties had not changed since endorsement but that were not renewed due to lack of resources to resubmit and revalidate these measures. Since NQF does not recommend measures for specific purposes (e.g. health plan assessment; population health surveillance, etc.) and methods for inclusion of measures are unclear we will not continue to update or characterize these measures in the compendium.

Alignment gaps and opportunities

Measurement efforts across the MCH programs and initiatives reviewed here are not aligned so as to advance collaboration, shared accountability, and collective improvement of MCH health and well-being outcomes. For example, only 13 of 61 measurement topics across four federal programs of focus (Title V MCH Block Grant, Title IV child welfare, Medicaid/CHIP, and MIECHV) are shared across these programs and in only two cases are the measures used derived in the same manner. The 13 topics addressed by more than one program mainly concern birth outcomes and immunization. Even well accepted Title V measures related to services and experiences of children with special health care needs are often not applied to the plans, providers, and services financed by Medicaid/CHIP.

Development and maintenance of an aligned and harmonized set of core MCH measures that could be usefully applied across programs and initiatives is an important opportunity in MCH measurement. It may be that a core set is needed for monitoring population health and well-being and a separate core set is needed for practice settings; however, these should be aligned and harmonized where doing so adds value and promotes learning and improvement and reduces measurement burden. Even high priority, minimal sets of core measures can be of great value.

Application gaps and opportunities

Many MCH measures are not accompanied by micro-data based on these measures. For example, the CMS PQMP measures exist but data is not collected based on them (in nearly all cases) nor is a centralized point of access to learn about and get help using these measures available. This is true for many measures. In addition, measures that address emerging priority areas (i.e., child well-being and flourishing, relationships, family, etc.) exist in measurement sets reviewed, yet they remain unapplied to programs and policies in which they could be used to drive action (i.e. standards, benchmarks, program evaluation, required reporting, etc.). For example, PQMP includes NIH-PROMIS measures related to family belonging and family involvement that may have value for practice-based use in promoting health and well-being but are not used for this purpose based on our review. A number of the life course indicators AMCHP identified in their set of measures relate to the health and well-being of women, children, and families and can be derived from national surveys. Yet, these are not widely applied across MCH programs and initiatives.

Equity gaps and opportunities

Health equity is characterized as the attainment of the highest level of health for all people, to include removal of any and all differences (disparities) in health that are avoidable, unfair, and unjust. Much of past work on reducing disparities for MCH populations ended up just measuring and describing disparities. Too little has been done to develop measures, collect useful data, and score and report data to elucidate a more comprehensive definition of equity and to drive change

in policies, programs, and practice. Gaps exist in terms of monitoring at the population level, as well as in practice settings. While collection of race, ethnicity, and language (REL) data has received increased attention as a topic, gaps remain and in many instances programs and systems do not collect REL data at the individual level and data collection continues to generally be limited to the overall geographic population. Without the ability to stratify MCH measures by factors such as race/ethnicity, income, gender, sexual orientation, children with special health care needs (CSHCN), disability status and the like, it is impossible to examine disparities or equity across different populations. The collection of demographic information for the purpose of stratification and subsequent examination of health disparities is an effort made by some of the programs reviewed, such as Title V. However, other initiatives and programs do not systematically collect demographic information in a way that allows for routine stratifications.

Translation gaps and opportunities

While efforts to translate measures and findings to key audiences exist among some programs, most programs do not prioritize data translation and accessibility to key audiences, such as community and local entities. Training in how to use measurement sets and data that can be used for city/county and smaller area analysis on MCH-related topics would help (e.g., American Community Survey data from the Census Bureau). Use of local level measure estimation methods and composite measures also holds promise for improving value and community-wide engagement around measurement findings. Translating existing data into actionable policy- and program-relevant narratives describing the determinants of health and well-being, and measuring community health and well-being needs to be done more systematically by states, academic institutions, and local organizations. This is particularly true in light of growing efforts to use collective impact approaches that require a shared understanding of current status and needs of the population and issue of focus.

Specification/validity gaps and opportunities

Most measures reviewed contained high level technical specifications, including, at the very least, numerator and denominator statements. However, in many cases information was lacking on detailed data collection procedures, development process or origin of many measures, and aspects of validation assessed, potentially limiting their consideration by programs and researchers despite their relevance or value. Also, this lack of information can lead to loss of historical information about how measures were developed and tested once they become a part of an identified measurement set without this development and validation history included in the documentation for measures. In some cases this will or has resulted in loss of hard-won knowledge essential to inform continued use and/or improvement in measures and needs to conduct validity studies afresh and ensure publication or official documentation of validation.

What priorities for MCH measurement emerged from these findings?

The MCH-MRN Strategic Agenda points to key opportunities to promote effective and harmonized MCH measurement across programs and initiatives at the national, state, and local levels. The Strategic Agenda also seeks to translate these findings into programs, policy, and practice. The processes and analyses conducted through the MCH-MRN led to identification of

strategic, high-level priorities and accompanying recommendations for action. The six high-level priorities and recommendations for action are outlined below

These high-level priorities are not necessarily listed in the order of importance for the field. However, MCH-MRN advisors were asked in a structured input tool to identify the MCH measurement priorities that they believed were the most important to address. Among 26 respondents, 40% considered addressing MCH measure "conceptual gaps" as the top, #1 priority. Approximately 20% of respondents considered promoting the use and application of under-utilized MCH measures a top priority, and another 20% considered barriers to equity analysis a top priority. In addition, about one-quarter of respondents identified positive health (such as flourishing) and family health as two of the top conceptual gaps to address-though a higher proportion of those included in the key informant interviews (n=29) conducted earlier in the agenda setting process emphasized the importance of filling measurement gaps in these areas.

What specific recommendations and actions can address these high-level priorities?

The MRN Strategic Agenda is an evolving resource which will continue to be modified and updated as input is provided, actions occur, and results are achieved. In this context, this section presents general recommendations to address each of the current MCH-MRN priorities. As described above, recommendations were generated from the CAHMI's key informant interviews, environmental scans, solicitation of input from MRN members, and ongoing identification of opportunities to leverage existing or emerging research, practice, and policy efforts.

High Level Priorities and Recommendations for Action

Priority 1: Fill key conceptual gaps, especially in topic areas such as: positive health, well-being, socio-emotional functioning, family/relationship factors, perinatal health, early and middle childhood, and social determinants of health.

Priority 2: Increase the use and application of under-utilized measures at the national, state, and local levels.

Priority 3: Address barriers to equity analysis through the collection and use of key person-reported and demographic data.

Priority 4: Improve data availability and translation at the local level.

Priority 5: Promote alignment across programs and practices to enable shared accountability for health and well-being outcomes.

Priority 6: Address gaps in measure specification and validity.

Priority 1: Fill key conceptual gaps, such as positive health, well-being and life satisfaction, family/relationship factors, socio-emotional functioning, perinatal health, early and middle childhood, and social determinants of health.

- *Recommendation 1.1: Prioritize filling positive health and family health conceptual gaps, as suggested by experts in the field.*

  Among key informant interview respondents, positive health and flourishing and family health emerged as two of the top conceptual gaps to address. Respondents pointed out that measuring family health is critical across the lifespan. When children are very young, optimal development requires safe, stable, and nurturing homes and other environments. As children grow older, their health continues to be dependent on their family's physical, emotional, material, and social circumstances. Therefore, strengthening and supporting families and ensuring their health is essential for ensuring health and well-being across the lifespan. Additionally, respondents highlighted the fact that the absence of negative experiences/factors/illness does not ensure the presence of well-being or supportive or protective conditions; alternatively, there can be positive assets and flourishing in the face of adversity. Several respondents also pointed out that increasing a focus on positive and relational health measures can help prevent researcher and community advocacy "burn-out" from a consistent focus on detriments and negative health. Measuring positive health and functioning—including resilience, engagement in life, resourcefulness, curiosity, persistence, and other aspects of positive mental health like a sense of emotional well-being, purpose, meaning, hope, and optimism—is aligned with the science of human development and thriving and the neurobiological sciences and may be key to stemming the tide on the persistent increase in mental, behavioral and emotional problems among US children, youth and families.

- *Recommendation 1.2: Leverage influential frameworks and initiatives to fill conceptual gaps.*

  Many frameworks and initiatives exist specific to or relevant to MCH measurement. The US National Quality Strategy is one such framework that could be influenced to focus more on MCH populations. Others include the Institute of Healthcare Improvement's 100 Million Healthier Lives and National Center for Vital and Health Statistics Data frameworks; as well as Child Trends' Child Well-Being Framework, the Robert Wood Johnson Foundation's Culture of Health Metrics. Several frameworks already prioritize measures in key conceptual gap areas. These include the Centers for Disease Control's Essentials for Childhood, the Center for the Study of Social Policy's Strengthening Families and Youth Thrive, and the CAHMI's emerging "New Science of Thriving/We Are the Medicine" frameworks.

- *Recommendation 1.3: Harmonize, evolve, and support use of measures related to social determinants of health specific to MCH populations.*

  In the United States and across the world, increasing attention has been given to social determinants of health (SDOH). Healthy People 2020, the Centers for Disease Control and Prevention, and the Health Resources and Services Administration all emphasize the need to take a "life course" approach in primary care and public health, which requires attention to SDOH as key contextual factors that contribute to healthy development, health potential, and lifelong well-being for children and families. Drawing substantially upon the initial definition and factors established by the World Health Organization,

numerous efforts are underway to define measurement in this area; however, few of these are focused on MCH populations. The MCH-MRN is conducting analyses, engaging with key stakeholders, advancing new tools, and developing collections of MCH measures related to SDOH that can be practically applied in pediatric, perinatal, and other settings. Our definition seeks to be comprehensive and inclusive of all factors that contribute to healthy child development which are not child-specific and bio-medical in nature, including household material well-being, personal and social well-being of parents and children, and child-family relationships.

Priority 2: Promote the use and application of under-utilized measures.

- *Recommendation 2.1: Identify a strategic suite of measures which address emerging priority areas, are under-utilized, and require application.*

  Several measures exist which do currently address emerging priority areas; however, these measures are under-utilized. One example includes measures specified within national surveys such as the National Survey of Children's Health (NSCH) and the National Survey of Children with Special Health Care Needs (NS-CSHCN). While the NS-CSHCN is no longer collected, the measures that were included in this national and state survey could be adopted or adapted for local use or other purposes. Additional measures that can be derived from the NSCH other than those included in the Title V National Outcome and Performance measures also hold great promise. Another example exists among the NIH-founded Patient Reported Outcome Information System® (PROMIS) – which has resulted in the development of a host of innovative measures of child and family health and well-being. These measures have not been well used outside of the context of a clinical research environment. One such measure is the *Pediatric Family Belonging* measure, which is a composite measure based on survey questions that ask children if they feel that they belong in their family, have strong relationships within their family, are treated fairly and with respect by their family, and get the help they need in their family, among other questions. Given the increased focus on relationships and context in child-health improvement efforts at the population and program level, innovative measures such as this have the potential for adaptation, validation, and use in settings beyond clinical research. To promote the usage of innovative measures such as this, the field first needs to identify suites of measures which currently address emerging priority areas but are not optimally applied for action. Methods to collect data directly from children, youth, and families and link across data systems are also called for and lack of such methods explains many gaps in use of measures. Several respondents to the MRN input tool noted the need to efficiently leverage current measures, to put our limited resources as a field to good use. The infrastructure for doing so is often underestimated and is largely non-existent in the MCH field at this time.

- *Recommendation 2.2: Leverage national surveys to promote the use and application of under-utilized measures.*

  As mentioned above, national surveys such as the National Survey of Children's Health (NSCH), the National Survey of Child and Adolescent Well-being (NSCAW) and many other contain untapped potential for increasing the use of measures at the local or

program levels that address emerging priority topics such as social/emotional well-being, school readiness, and family and peer relationships. Additionally, follow-back surveys are one way to produce follow up and potentially longitudinal data, which would promote more learning, usage, and application of these measures as well as fill critical gaps in knowledge to improve MCH outcomes.

Priority 3: Address barriers to equity analysis through the collection and use of key person-reported and demographic data.

- *Recommendation 3.1: Promote a re-examination of socio-economic data collection practices in light of new protective statuses.*

  Legal restrictions (e.g. on sharing health information) prevent some state Medicaid/CHIP programs and health plans from collecting and sharing some demographic information without permission. For these reasons, the majority of the health care quality measures included in HEDIS, PQMP, and CHIP/Medicaid programs do not contain key socio-economic data components. These restrictions create troublesome barriers to assessing health equity among these populations. Without the ability to stratify the data by factors such as race/ethnicity, income, gender, sexual orientation, children with special health care needs (CSHCN), disability status and the like, it is impossible to examine disparities across different populations with regards to the quality of care received. Existing regulations, norms, and data systems that prohibit demographic data collection need to be re-examined, clarified, and modified.

- *Recommendation 3.2: Explore how to promote safe socio-economic data collection practices.*

  Even when not legally prevented from doing so, many measurement users nonetheless shy away from demographic data collection for fear of being accused of using data for discriminatory purposes. Efforts must advance standards for safe and reliable socio-economic data collection practices, both to protect respondents and to advance commonly accepted approaches to equity analyses.

- *Recommendation 3.3: Support the inclusion of self-reported sexuality measures.*

  Very few measures, measure initiatives, or national surveys ask for participants' sexual orientation or gender identity. This gap prevents the awareness and analysis of important health disparities among LGBT populations. Including children and families in the development of these measures is essential to ensure that the language and specifications resonate.

Priority 4: Improve data availability and translation at the local level.

- *Recommendation 4.1: Use local-area estimation techniques to increase the availability of MCH data at the county, city, and community level.*

  Several respondents to the MRN input tool highlighted the critical need to make data available at the county, city, and community level. There has been a 'hunger' in the field for this data for decades, as it is critical for decision making, and may uncover more

distal factors that can provide new understanding for health promotion. Local-area estimation techniques need to continue to be tested and applied to suites of data considered the most critical for immediate use at the local level. The CAHMI's pilot 'local area estimator' is one tool which could be leveraged to advance immediate work in this arena. Developing technical assistance tools and guides to using Census and other local data is another opportunity, with some preliminary work underway.

- *Recommendation 4.2: Provide training and technical assistance to communities in the production and use of local-area data.*

  Local-area data can empower communities, and lead to truly innovative community-based solutions. Given the current lack of resources in the field to generate local-area data for the wide array of data-points needed and of interest to cities, counties, and communities in the US, communities can be armed with the tools to produce, analyze, and translate local-level area data. Routinely available and rigorous training and technical assistance can provide community partners with the skills they need.

- *Recommendation 4.3: Support local and practice-based collection of data on measures of high value.*

  Many validated measures exist for national and/or state data collection mechanisms. Tools, like the HRSA-supported online Well Visit Planner and similar tools can be a way to collect data at the patient or local community level and provide a real time data base to monitor health needs, system performance and patient and population well-being. Strategies developed in the Infant Mortality Collaborative Improvement and Innovation Network (CoIIN) efforts led by HRSA identified ways to accelerate the availability of preliminary vital statistics data related to birth outcomes, supporting hospital, local, and state level quality improvement and innovation. Specific efforts to identify feasible and sustainable tools to collect person-reported data that can also be integrated into electronic health records and other data systems is essential as are methods to effectively use crowdsourcing measurement methods and big data.

Priority 5: Promote alignment across programs and practices to enable shared accountability for health and well-being outcomes.

- *Recommendation 5.1: Create a core set of social determinants of health measures to promote alignment across practices and programs.*

  As noted, input provided for the formation of this agenda highlighted the necessity of standardized, feasible, and comprehensive social determinant of health measures, both to address the underlying causes of maternal and child health disparities, and to encourage cross-sector partnership. However, concurrently, there is a recognition that many of these measures already exist in the field, with a lack of agreement and alignment. There is a growing necessity to explore the development of a core set of social determinants of health measures to promote alignment across practices and programs.

- *Recommendation 5.2: Promote alignment across federal programs to enable shared accountability.*

  As noted earlier, only 13 of 61 measurement topics across four federal programs of focus (Title V, Title IV, Medicaid/CHIP, and MIECHV) are shared by multiple programs.

There exists a strong need for a unified set of indicators across federal programs and agencies if these programs and agencies are to share accountability and partner fully in improving MCH outcomes and systems performance. The MRN is in a unique position to provide guidance about the harmonization and alignment of measures to support program accountability and comparability.

- *Recommendation 5.3: Data linkage can help promote alignment across programs.*

  In cases where programs are unable to collect recommended, standard data, data linkages to existing data can be an option to explore. Linking to other data sources can be a cost-effective option for programs to integrate data which will help them analyze and interpret the effectiveness of health and well-being initiatives.

Priority 6: Address gaps in measure validity and specification.

- *Recommendation 6.1: Promote publication of validity studies among journals.*

  Validated measures are often those which are most readily accepted by providers and policy initiatives. Additionally, participants in the development of the MRN agenda pointed out that many measures which have been developed are likely not being used or applied due to lack of publication of the validity analyses conducted in developing and gaining inclusion of measures in MCH program/initiatives measurement sets. In other cases, such validity assessments were not conducted to address enough components of validity (e.g. face, construct, content, concurrent, divergent, external, and internal validity) or were not done with enough scientific rigor. It is worth examining how to facilitate completion and publication of validity studies quickly, and exploring with academic journals the promotion/publication of validation studies - including validation studies among different and previously studied samples. In the rush to develop indicators, often validity studies were done but not published and with the passage of time it may require new research to validate measures afresh.

- *Recommendation 6.2: Address specification gaps among priority measures.*

  Until measures are clearly defined with transparency and clarity, the use and application of the measures, especially across programs, is limited. For example, in the federal home visiting program, one performance measure calls for reporting on the percentage of prenatally enrolled participants who deliver a preterm infant; however, this measure does not take into account the home visiting dosage, which limits the ability to discuss the impacts of participation in the program on preterm birth. There is benefit to fully assessing other specification gaps which exist among many priority measures.

How is the MCH-MRN moving from recommendations into action and change?

The MCH-MRN structure offers mechanisms and actionable resources to support MCH stakeholders in their knowledge and use of MCH measures and in application of measures into policies, programs, practices, and processes. The MCH-MRN uses five key levers for change. (See Appendix B for a diagram of the MCH-MRN Theory of Action.)

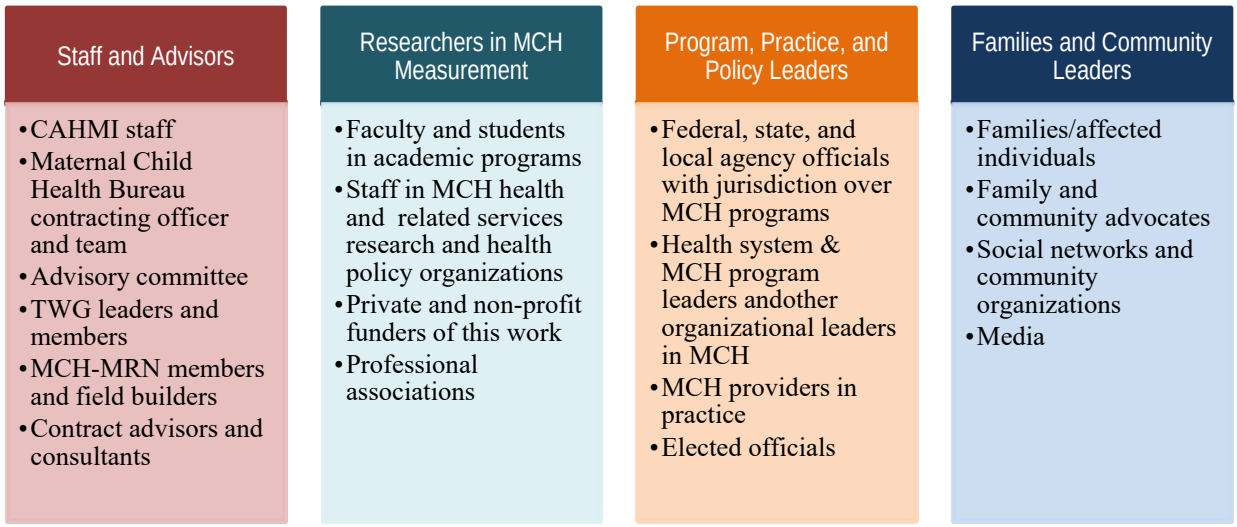
1. Shared vision, strategic agenda, and common framework,
2. Applied multi-disciplinary Network that organizes MCH leaders for action,
3. Research to advance methods and knowledge,
4. Actionable resources, including a web-based measures compendium and other online resources, and
5. Public-private funding for a sustainable focus on MCH measurement.

Two of these—organizing leaders and actionable resources—are discussed further below.

Organizing MCH Leaders for Action to Improve Measurement

The MCH-MRN engages a diverse, multidisciplinary group of professionals with the skills and commitment to improve MCH measurement systems. (See Figure 3.) Engaging a wide array of stakeholders helps to ensure that the MCH-MRN approaches reflect the concept that health outcomes and trajectories are influenced by a range of factors from within and outside of the health sector. MCH-MRN members and other key stakeholders participate in MCH-MRN initiated and self-directed research projects, professional training and education, and dissemination efforts. Network members informed and facilitated development of this Strategic Agenda to improve MCH measurement and helped to identify gaps, guide priority setting, and refine recommendations for action. MCH-MRN collaborations guide implementation of the agenda, as well as to advance measurement research and innovation.

Figure 3 Key Stakeholders in MCH Measurement



The MCH-MRN's Technical Working Groups (TWGs) are "operational arms" to put the Strategic Agenda, priorities, and recommendations into action. A TWG under the MCH-MRN is a group of individuals who choose to come together for the explicit purpose of addressing an MCH measurement gap or opportunity area identified. TWG participants include MCH researchers, advocates, practitioners, program specialists, policymakers, and others. The TWGs are provided with resources and support by the CAHMI (e.g., a TWG Toolkit, technical

assistance, frameworks and guidelines for measurement development and use, and MCH measurement compendium). (See Appendix A Child and Adolescent Health Measurement Initiative Four Part Model of Measurement for Action.) At a minimum, the TWGs produce at least one of several products: (1) specify a measurement "charter" and advance a more detailed agenda and plan for research, (2) conduct reviews and develop and set forth consensus statements, (3) apply for funding to support priority research and work, publish on priority topics, (4) and/or make program/policy recommendations to the MCH-MRN Strategic Agenda or key stakeholders in MCH measurement (including framework and/or existing measurement set sponsors).

Currently, five TWGs are in operation, each of which are addressing specific gaps and opportunities outlined in the MCH-MRN Strategic Agenda. For 2018-2019, these include: 1) Positive and Relational Health TWG, 2) Mental and Behavioral Health TWG, 3) Social Determinants of Health TWG, and 4) Family Health TWG, and 5) Family Engagement TWG. The development of a TWG on women's and perinatal health is under consideration.

The Strategic Agenda priorities inform cross-cutting work among the TWGs. For example, several TWGs are looking at opportunities to support local measurement. Efforts to advance measurement related to "trauma informed care" is primed to be folded into the Positive and Relational Health or similarly relevant TWG. All are leveraging what we know from existing measurement research and the MCH-MRN compendium of measures. (See Appendix A Child and Adolescent Health Measurement Initiative Four Part Model of Measurement for Action.)

Refining and disseminating actionable resources for MCH measurement

Maintaining accessible MCH measures and data in the public domain is imperative to achieve impact. Centralized, freely-available, online information on existing MCH measures empowers stakeholders in all professions to evaluate the scope of measures available and draws attention to gaps and opportunities for innovation and coordination across programs and sectors. CAHMI is maintaining and updating an actionable MCH measures compendium and an MCH-MRN online portal. The compendium of MCH measures was initially developed from the results of the measurement scan summarized above. The compendium is an essential tool for disseminating MCH measurement knowledge and is searchable by topic, target population, associated measurement initiative or program, data source, and other parameters. The compendium is reviewed and updated annually, though inclusion of other measurement sets is a function of need and resources. During 2018, the compendium is being updated to: 1) review existing measures to ensure continued accuracy and identify changes from the measure set developers; 2) add new or retire existing measures as appropriate from current compendium measure sets; and 3) refine the measurement framework.

In addition to the interactive compendium, the MCH-MRN portal includes other resources such as one-page summaries of the MCH measure sets, information about how measures are developed and validated, updates of TWG work, and information regarding the strategic agenda for MCH measurement**.**

Conclusion

As national priorities shift toward a focus on the overall health and well-being of children, it is more critical than ever that the field respond to the need for systematic and collaborative MCH measures and is able to move toward shared accountability for MCH measurement processes.

Measuring the health and well-being of the MCH population in effective and collaborative ways must continue and accelerate in order to turn the tide of poor outcomes and realize the promise of promoting healthy development early and across the life span. This potential is made apparent by both our scientific knowledge and lived experiences. Nevertheless, much MCH measurement is still carried out by experts and leaders working within their own relatively narrow programs and disciplines and does not support a broader agenda for improving MCH needs, services, and outcomes, through a transdisciplinary, transformative, and translational approach.

A robust, purposeful, and sustainable MCH-MRN is essential to advance the actions needed to address gaps and support the application, improvement, and effective use of measurement strategies across the diverse landscape of systems, agencies, and programs responsible for protecting the health and well-being of mothers, children, and families. The Network and its Strategic Agenda are critical at this juncture for several reasons. First, as MCH delivery systems evolve to engage professionals in a diverse range of fields spanning beyond traditional health care providers, measures are needed to capture usable data in a wide range of settings. The construction of a measurement system that can satisfy the demand for robust and applied MCH metrics by diverse users requires intentional, multidisciplinary collaboration. Second, ongoing efforts by the MCH-MRN will: permit ongoing assessment of the MCH measurement landscape, continue a robust measurement review process, anchor a shared vision and roadmap to coordinate efforts in priority areas, and create opportunities for interdisciplinary research and innovation. Third, embracing the complexity of measurement and promoting the adaptability of emerging paradigms, such as the life course model, involves the engagement of diverse stakeholders through a multi-disciplinary Network. Finally, the MCH-MRN provides a centralized structure where MCH measure and data users from various backgrounds can unite to identify opportunities for increasing effective measurement in research, policy, and practice settings and translating data into action at the national, state, and local levels.

Ultimately, the MCH-MRN Strategic Agenda seeks to advance collaboration and shared accountability toward improving MCH outcomes within and across programs and systems, while aiming to support an era of innovation in MCH measurement to optimize and ensure the health potential of our nation’s mothers, children, and families.

Appendix A. CAHMI Four Part Model of Measurement for Action

5 Level Framework for Conceptualizing Measures	6 Stage Measurement Development Process	7 Criteria for Measurement Review and Endorsement	6 M's for Implementation and Improvement
Level I. USE Audience (e.g., policy makers, payers, providers, families, consumers) and purpose (e.g., use for surveillance, accountability, improvement, engagement, etc.).	**Stage 1**: Engage professional experts, families/consumers, and other stakeholders to establish measure and set relevance, evidence, framework and approach.	**Criteria 1:** Relevant and meaningful.	**Model**: Use-case specific measure matrix and conceptual logic model and change model.
Level II. AIMS Broad and specific outcomes seeking to influence (e.g., healthy development, staying healthy, getting better when sick, living well with illness, managing transitions)	**Stage 2**: Starting point measurement proposal for stakeholder, cost, and feasibility review.	**Criteria 2:** Based on best available evidence.	**Measures**: Detailed specifications for each use case (design based).
Level III. TARGET POPULATION (e.g., age, developmental staus, risk, geographic populations)	**Stage 3**: Specify methods options, issues, design field test.	**Criteria 3:** Demonstrated validity and reliability based on appropriate methods.	**Methods**: Detailed methods for implementing measurement specification for each population and setting/use case.
Level IV. ACTION FACTORS / THEORY OF CHANGE (e.g., protective and risk factors, process and policy requirements, program aims)	**Stage 4**: Conduct field test, including reporting and communication models.	**Criteria 4:** Actionable policy, program, and/or intervention strategies available or advanced with measurement.	**Messages**: Data scoring, grading, reporting format, and messages (specific to user/audience and purpose).
Level V. UNIT OF ANALYSIS & INFLUENCE: (e.g., geographic area, program, clinic)	**Stage 5**: Refine measure(s) specifications for each application and reporting criteria.	**Criteria 5:** Feasible data collection and reporting strategies.	**Meaning**: Confirm meaning made from measures and adapt methods and messages as required.
	Stage 6: Document scientific and technical methods, implementation, dissemination, and maintenance requirements.	**Criteria 6:** Parsimony and added value.	**Maintenance**: Establish credible and sustainable resources and processes for routine review and to support consideration of measures by researchers, endorsing bodies, and new and exiting users. Learn, publish, and build field capacity to ensure progress.
		Criteria 7: Clear requirements fo sustaining measure use, maintenance, and improvement over time.	

FOUNDATIONS:
Stakeholder and expert derived
Design-based and outcomes-based goals, premises, and principles
Review processes, parameters, and periodicity

Start where you want to end up!

Appendix B.

MCH-MRN Theory of Action

Coordinated by CAHMI
MCH-MRN
Maternal & Child Health Measurement Research Network

If we do the following...	...then we will impact the following	... and we will achieve the following results.
Fill key conceptual gaps • Gain support for filling priority conceptual gaps. • Support rapid research and action. • Align with and leverage existing frameworks and initiatives.	• Measures to fill conceptual gaps. • More information about important aspects of health and well-being. • New knowledge about how to promote positive health and well-being.	• Improved capacity to monitor health and well-being of MCH populations across the life course. • More stakeholder engagement. • Greater equity for MCH populations. • Better informed policy, program, and family leaders. • More information for planning across the MCH workforce, programs, and initiatives. • Use of more effective measures, tools, and approaches by providers in practice. • Increased use of community-level measures and data to drive action, build knowledge, and improve well-being. • More capable and prepared measure and data users and developers. • More efficient and effective use of measures, data, and the resources it takes to apply them. • Greater shared accountability for progam results and health outcomes.
Increase use and application • Identify a sets of measures and promote their use to address emerging priority areas. • Leverage exisiting measures for strategic use.	• Existing measures applied to fill gaps and address emerging questions. • More data to understand community assets, risks, and context. • Better use of existing measurement resources.	
Address barriers to equity analyses • Advance measurement, data collection, and communication practices for socio-economic, racial-ethnic, and gender topics. • Promote data collection methods that protect individuals and fit with law.	• More data to monitor disparities in access, health determinants, and well-being. • Data to drive change toward increased equity. • New knowledge about equity and disparities.	
Improve data use at local level • Use local area estimation techniques. • Develop training and technical assistance to support local data use.	• More data and measures used to inform and inspire community programs and collaboration. • Data to drive change toward increased health of communities and residents. • New knowledge about well-being and impact of efforts at local level.	
Promote alignment & shared accountability • Create common core sets of measures relevant across programs. • Promote alignment across programs for shared accountability. • Promote data linkages.	• Better cross-program information. • More efficient use of measurement and data. • Better diffusion of measures across programs and initiatives. • More shared accountability.	
Increase validity and specification • Identify and promote conduct and publication of validity studies in proirity areas. • Address specification gaps among priority measures.	• Improved documentation andquality of existing and emerging measures. • Increased use of measures across programs and initiatives.	

Child and Adolescent Health Measurement Initiative Key MCH-MRN Online Resources

- MCH Interactive Measures Compendium. Available at: www.childhealthdata.org/browse/mchmeasurement/compendium
- MCH Measure Set Profiles. Available at: http://childhealthdata.org/browse/mchmeasurement/measure-set-profiles
- MCH-MRN Measurement Portal. Available at: http://childhealthdata.org/browse/mchmeasurement
- National Survey of Children's Health data findings on Title V measures. Available at: http://childhealthdata.org/learn/NSCH

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