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National Association of
Chronic Disease Directors

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Introduction

The Problem of Diabetes
Prevalence of diabetes (type 1, type 2 and Gestational Diabetes) is increasing and as of today affects 2 out of every 5 Americans.\(^1\) For women, the risk for the average 20 year old woman increased from 27% in the 1980s to 40% today. Additionally, besides the increased prevalence, the cost of diabetes is rising at a higher rate than overall medical costs: $245 billion in 2012 for all types of diabetes and Gestational Diabetes costs $636 million annually.

PREVENTION UPSTREAM:
Instead of expending all resources and energy on rescuing people, why not stop the problem from even happening? This is not to say that the problem can be totally eliminated – or at least not right away, but there may be fewer people to rescue downstream.

Prevention “Upstream” is a very old public health concept... starting in a community always pulling people out of the river as they tried to cross... so they hired more people and bought more rescue equipment, until someone suggested going upstream where the river narrowed, and building a bridge.

You can’t go further upstream than in utero... Rarely do you find such an easily identified high risk population of over a half million women and infants each year, than with Gestational Diabetes.

\(^1\) Gregg, E, Sood, M; The Lancet Diabetes & Endocrinology, online August 13, 2014
Gestational Diabetes
Pregnancy can predict and sometimes exacerbates risk and future chronic diseases such as Gestational Diabetes and subsequently obesity, type 2 diabetes, hypertension or heart disease.

Gestational diabetes mellitus (GDM) is a condition of carbohydrates intolerance of varying severity that begins or is first recognized during pregnancy, and is one of the most common complications of pregnancy. In some cases, GDM is actually type 2 diabetes that has not previously been diagnosed, but for most patients the glucose intolerance disappears soon after delivery. The prevalence of GDM varies because of different screening and diagnostic criteria, populations, race, ethnicity, age, and body composition. The March 2013 NIH Consensus Development Conference Statement on Diagnosing Gestational Diabetes estimates the prevalence rate of 6-7% of all pregnancies with a live birth.²

“Gestational Diabetes presents a lifetime challenge to the health of mother and offspring”

Today, gestational diabetes is not merely a pregnancy complication but a lifetime challenge for the mother and the child, as we are in an era where the prevalence of the metabolic syndrome and diabetes itself is increasing in all demographics including women of gestational age. Since 2012 the Standards of Medical Care in Diabetes not only called for women with risk factors to be screened for undiagnosed type 2 diabetes at the first prenatal visit, but also defines gestational diabetes as ‘diabetes diagnosed during pregnancy that is not clearly overt diabetes and presents additional need for screening and diagnostic procedures.’³

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2 National Institutes of health, Consensus Development Conference Statement: Diagnosing Gestational Diabetes Mellitus, March 4-6, 2013
3 American Diabetes Association in Diabetes – 2015, Diabetes Care, Supplement
Why the Interest Now?

- Prevalence rates range from 7-14%, with anticipated growth up to 18%\(^4\)
- Currently affects over 240,000 pregnancies annually\(^2\)
- Women with GDM have Relative Risk of 7.4 of developing type 2 diabetes in next decade\(^5\)
- Women with both GDM and Pre-Eclampsia are even more at risk – Are 18 times more likely to develop hypertension and early heart disease\(^6,7\)
- Long-term adverse health outcomes for both mother and offspring
- Studies show type 2 diabetes can be prevented or delayed by long-term follow-up care and risk factor reduction interventions\(^8\)

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\(^4\) Lawrence JM, Chen W, Black MH, Sacks DA, Hsu JW. Prevalence and timing of postpartum glucose testing and sustained glucose dysregulation after gestational diabetes mellitus. Diabetes Care 33:56576, 2010

\(^2\) National Institutes of health, Consensus Development Conference Statement: Diagnosing Gestational Diabetes Mellitus, March 4-6, 2013

\(^5\) Barclay, L. Lifetime Risk for Type 2 Diabetes Increased in Women with Gestational Diabetes, Lancet 2009; 1731-1740

\(^6\) Bellamy L, Casas JP, Hingorani AD, Williams D. Type 2 Diabetes after gestational diabetes; a systematic review and meta-analysis. Lancet 2009: 37:1773-9


Purpose of this Report

This report provides the reader an overview of the importance and challenges of Gestational Diabetes (GDM), that the incidence and prevalence are increasing and that GDM should no longer be considered a short term pregnancy related condition.

The report includes the following:

- reflects the history of the Women’s Health Council and its efforts to address Gestational Diabetes. The Women’s Health Council, established in 1995, is one of several councils of the National Association of Chronic Disease Directors which address key chronic diseases or cross cutting issues;

- is aimed at healthcare providers who give women’s health, maternal child health and/or chronic disease care. The partners of the Gestational Diabetes Collaborative Better Data Better Care represent both health care providers and public health practitioners; and

- recommends actions to improve surveillance and accuracy of data, improve healthcare provider knowledge and behaviors and enhance health/clinical systems to provide comprehensive care for women with Gestational Diabetes to prevent/delay type 2 diabetes.

Partners utilized evidence based strategies and conducted translational quality improvement interventions to address gaps in data quality, health systems and clinical care policy and systems. Their accomplishments, outcomes and lessons learned are demonstrated in the following pages.

The authors of this report celebrate the accomplishments and lessons learned by our state and tribal partners. Their collaborative efforts with partners allowed creative thoughtful products and programming. A companion report on the state and tribal initiatives has also been published.
The Women’s Health Council, National Association Chronic Disease Directors (NACDD), has had an interest in women’s issues and has addressed the gaps in programming, services or policy since 1995.

In 2002, the Council began investigating depression and found that women with diabetes were more at risk for depression, both clinical depression and postpartum depression. At the same time, the council began developing an interest in women and the lack of physical activity. These two interests led to collaborative partnerships with the United States Department of Health and Human Services (U.S.H.H.S.) Office on Women’s Health and Centers for Disease Control’s (CDC) Division of Diabetes Translation. Since 2002, projects have focused on Diabetes and Women: “Women, Diabetes and Depression”, “Women, Obesity, Diabetes and Physical Activity”, and “Gestational Diabetes.”
Phase I – Gestational Diabetes Validation Project

5 States conducted a data validation study to assess the quality of GDM data utilizing data from

- Birth Certificates
- Pregnancy Risk Assessment Monitoring System (PRAMS)
- Hospital Discharge Data
- Medical Records

Cross comparisons were made using multiple sources of 2004 GDM data. The results of this validation process revealed that a diagnosis of GDM was omitted from 38% of the 277 birth certificates reviewed, although the diagnosis was found in 62% of maternal medical records for corresponding patients. 26% of the participants with risk factors for GDM lacked documented testing and/or follow-up for GDM, and 36% did not have an elevated glucose level or a GDM diagnosis. Only 50% of the medical records reviewed had the appropriate International Classification of Diseases, Ninth Revision (ICD-9) code (code 648.8) confirming the diagnosis of abnormal glucose tolerance during pregnancy. In addition, only 5% of all the medical charts reviewed documented follow-up postpartum glucose testing and care or referrals for preventive care.9

9 Owens-Gary, M, Ware, J. Interventions to Increase Access to Care and Quality of Care for Women with Gestational Diabetes. Diabetes Spectrum Volume 25, Number 1, 2012
Lessons Learned from Validation Study

**Surveillance Lessons Learned**
- Inconsistencies in birth certificates across states
- No universally accepted “Gold Standard” for GDM diagnosis and treatment
- Lack of documentation for GDM testing/results and diagnosis and follow-up

**Care Lessons Learned**
- Documentation of diagnosis and care is lacking in prenatal, hospital and discharge data
- Women may not know or understand risk for developing T2D, and how to reduce risk
- Women may not receive appropriate postpartum follow-up

**Care Lessons Learned from the Literature**
- Less than 50% with GDM obtain a postpartum glucose test\(^6\)
- Linkages between OB-GYN care and primary care are often missing
- Fewer women with a history of GDM receive an intervention for weight management, physical activity from their provider than women without diabetes\(^10\)

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\(^6\) Bellamy L, Casas JP, Hingorani AD, Williams D. Type 2 Diabetes after gestational diabetes; a systematic review and meta-analysis. Lancet 2009: 37:1773-9

Goals of the Gestational Diabetes Collaborative

Foster collaboration
Improve GDM surveillance
Develop interventions to improve care
(e.g. Provider and patient education)
Prevent or delay Type 2 Diabetes through postpartum glucose testing, follow-up, and lifestyle coaching
Gestational Diabetes Strategies

The Collaborative utilized the following 10 strategies to accomplish their goals.


2. **Improve GDM/diabetes surveillance** in prenatal clinics, hospital charts, birth certificates and hospital discharge data.

3. **Ensure providers awareness of practice standards and GDM issues of care** through webinars, grand rounds, symposiums, on-line CEU modules, etc.

4. **Increase awareness of GDM complications and long-term risks in Women with GDM.** Make available educational materials for consumers and providers. Stress risk of type 2 diabetes for mother and offspring (before delivery).

5. **Encourage system changes in clinics.** For example:
   - Better documentation of prenatal and postpartum care
   - Prenatal/postpartum protocols and training for staff
   - GDM chart identifier system
   - Postpartum visit checklist
   - Education materials in an exam rooms
   - Standing orders for postpartum glucose testing
   - Lab services provided on site at clinic

6. **Improve discharge planning for women in GDM.** Examples: Discharge planning checklists include GDM instructions, provide Lab slip for 6 week pp glucose test, referrals for weight management or other risk reduction behavior coaching (Ref: Kim C, et al. Preventive Counseling Among Women with History of GDM. Diabetes Care 30:2489j-2495, 2007.)

7. **Promote postpartum testing**, for example: mail-out reminders, incentives for completed visits. (Ref: Clark H, et al.)
Do postal reminders increase postpartum screening of DM in women with GDM? AJOB&GYN. June 2009.)

8. **Conduct marketing research** to determine enablers and barriers for intervention, e.g. qualitative research, focus groups, interviews, surveys, etc.

9. **Develop partnerships to deliver your messages.** Promote consistent messaging about GDM risk and follow-up in a variety of venues (WIC, Immunizations, Family Planning, etc.)

10. **Develop methods to bridge gap between OB-GYN and primary care.** Examples: Encourage OB-GYN referral of patient back to primary care for follow-up. Develop a form letter OB providers can use for referral. Encourage all medical intake forms to include GDM, including pediatricians so offspring of mothers with GDM can be monitored.

These ten strategies were further refined and reduced to compliment the Chronic Disease Domains:

- **Enhance the validity of GDM data and expand surveillance.** (Domain 1: Surveillance and Data)
- **Increase postpartum and on-going diabetes testing and follow-up among women with GDM.** (Domain 3: Interventions to improve effective delivery and use of care)
- **Determine present knowledge, attitudes and practices of providers and women with GDM and facilitate positive changes of knowledge and behaviors among providers and women with GDM.** (Domain 4: Community Linkages)
- **Identify or develop resources/programs that effectively address diabetes management, diet and physical activity intervention for women with GDM/history of GDM.** (Domain 4: Community Linkages)
- **Encourage system changes in hospitals/clinics.** (Domain 3: Interventions to improve effective delivery and use of care)

These strategies, the activities and the accomplishments of the Collaborative partners are reflected in this final report document.
Collaborators

National Collaborators

CDC Division of Diabetes Translation
CDC Division of Reproductive Health
Association of Maternal/Child Health Programs
National Chronic Disease Directors (NACDD)
NACDD Women’s Health and Diabetes Councils
United States Department of Health and Human Services (USDHHS) – Office of Women’s Health

Collaborating States

Arkansas State Department of Health
Florida Department of Public Health
Idaho Department of Health and Welfare
Missouri Department of Health & Senior Services
North Carolina Department of Health & Senior Services
Ohio Department of Health
Oklahoma State Health Department
Utah Department of Health
West Virginia Department of Health and Human Resources

Collaborating Tribal Organizations

Alaska Native Tribal Organization/SouthCentral Foundation
Chickasaw Nation
Choctaw Nation
Utah Navajo Health System
The GDM Collaborative Better Data Better Care developed this model to direct projects in their evidence based assessments, quality improvement strategies and activities.
# Internal and External State Collaborators

Collaborative states and tribes developed both internal and external partnerships to accomplish their strategies and activities.

## Internal State Collaborators

- Chronic Disease Program
- Diabetes Prevention and Control Program
- Vital Records Section
- Maternal Child Health Programs
- Health Promotion Programs
- Behavioral Risk Factor Survey Project
- Epidemiology Services
- Wisewoman Project
- Women’s Infants and Children’s Nutrition
- Immunization Program
- Mental Health/Behavioral Health Programs

## External State Collaborators

- Diabetes Associations
- Diabetes Educators
- Dietitian Associations
- Diabetes Advisory Groups
- Medicaid
- Mental Health
- March of Dimes
- Community Health Centers, FQHCS
- YMCA
- Universities
- Prenatal/Perinatal Centers
- Hospitals and Clinicians
- Hospitals Associations
- State ACOG
- Primary Care Association
- Family Planning
- PROs
- Native American Health Boards
- Managed Care
- Prenatal/Perinatal Task Force
- Physicians/Nurse Practitioners/Midwives
Gestational Diabetes Collaborative Initiative Challenges

• Making Gestational Diabetes a priority for both Maternal Child Health and Chronic Disease

• Understanding that the weight gain/obesity prior in pregnancy and following places the woman and her offspring 7 x at risk for developing type 2 diabetes

• Capitalizing on a captive audience for Diabetes Primary Prevention activities

• Incorporating this initiative into an already full plate of other programs and initiatives

• Enhancing the collaborative efforts between Chronic Disease and Maternal Child Health Programs

• Collecting and analyzing the needed data resources
Strategy: Enhance Surveillance and Validate GDM Data

- Prenatal Clinic Records
- Hospitals Charts
- Birth Certificates
- Hospital Discharge Data
Data Achievements

All Collaborative Partners conducted a data source inventory, collected data and states published a GDM Prevalence Report.

Gestational Diabetes was added to Tribal Diabetes Data Registry (Chickasaw Nation, Choctaw Nation and Utah Navajo Health System).
Documentation Achievements

All collaborative states and tribes now use the 2003 electronic Birth Certificate form.

- Utah Project showed 30% increase in GDM reporting on birth certificates by providing a modified maternal worksheet and training for hospital medical records personnel.

- Chickasaw, Choctaw Nation and Navajo Health Unit partners assessed electronic medical records utilized in their Women’s Clinics and determined a need to develop GDM templates to capture needed clinical information and enhanced diagnostic and treatment policies to provide and improve care.

Provider Knowledge, Attitudes and Practices Surveys Accomplished

Accomplished
- Point in time survey was conducted by West Virginia WIC clinics.
- Utah Navajo Health System conducted a staff needs assessment.
- Idaho, Ohio, Utah and West Virginia conducted health care providers surveys.
- Idaho surveyed certified diabetes educators.

Lessons Learned
- Less than 1/3 of providers were aware of the high risk of type 2 for women with GDM.
- Providers lacked the knowledge, policies and tools to adequately provide quality care.
Patient Knowledge, Attitudes and Practices Surveys Accomplished

Result

• Ohio conducted postpartum focus groups among women who had GDM in three high risk populations to determine their needs and there was little consensus on messaging types or information.

• Utah conducted follow-up survey of women receiving postpartum information packets to determine effectiveness and patient satisfaction with the packets. The packets help remind need for postpartum check-up with glucose screen and need for convenient appointment scheduling.

• Chickasaw Nation collaborated with Boston University on conducting focus groups concerning risks, health beliefs, barriers/facilitators and specific interventions among postpartum native women with GDM and cardio-metabolic disparities. Results reflected a need for simple text messaging with strong support networks.
Lessons Learned

- State projects often do not have direct access to data and lack of epidemiology or statistical staff makes it difficult to obtain or interpret data.

- Data on GDM in ethnic and racial populations such as American Indians are scarce.

- Interpretations of the data vary greatly by the source.

- All but 1 of the state partners had access to PRAMS data, yet only two added GDM questions to the core questionnaire, and only 3 states were able to add questions to the BRFSS data set.

- Data collected by states are not easily accessible to providers and the public.

- Data on postpartum visits and glucose testing are not available, and if collected not readily accessible.

- While WIC patients receive some education about risks of GDM, there are few resources available for follow-up after the 6-week check-up.

- While CDEs provide excellent information about GDM, their services are not readily available to high risk populations like women on Medicaid.
Strategy: Develop Interventions to Improve Care and Prevent Type 2 Diabetes

Collaborative Partners developed interventions in a variety of settings; 
Health Department Maternity Clinics 
Community Venues 
Tribal Women’s Services and Diabetes Centers 
Academic Centers
Achievements in Professional Education

- User Friendly State Consensus Guidelines and/or GDM Guidelines for screening, diagnosis and follow-up were developed. (Arkansas, SouthCentral Foundation, Chickasaw Nation, Choctaw Nation, Missouri, North Carolina)

- Professional Webinars/Video Conferencing were conducted. (Arkansas, North Carolina, Ohio, Oklahoma, West Virginia)

- Public/Professional Summits were provided. (Arkansas, Idaho, North Carolina, Ohio, Oklahoma, Utah, West Virginia)
Patient/Public Education Achievements

- All states and tribes developed culturally and literacy appropriate patient brochures, fact sheets, media messaging or magnets. (Alaskan Native Consortium, Arkansas, Chickasaw Nation, Florida, Idaho, Missouri, North Carolina, Oklahoma, Utah, Utah Navajo Health System and West Virginia)

- State websites with patient education resources were developed. (all states)
**Clinical System Achievements**

- Clinical Care Systems Change – diagnostic, treatment and follow-up enhanced policies were developed. (Arkansas, Alaskan South Central Tribal Consortium, Chickasaw Nation, Choctaw Nation, Utah Navajo Health System, West Virginia)

- Tele-medicine Gestational Diabetes Self Management Education Program was developed and piloted tested. (Arkansas)

- Postpartum – type 2 diabetes prevention education component added to clinical protocols. (Chickasaw Nation, Choctaw Nation, Utah Navajo Health System)
Postpartum Achievements: Data, Enhanced Documentation and Clinical Care

- MCH Newborn Home Visiting Programs are beneficial for counseling on blood glucose screening or lifestyle interventions. (Oklahoma, West Virginia)
- Tribal interface with Wellness programs enhanced postpartum lifestyle interventions. (Chickasaw Nation and Choctaw Nation)
- Postpartum follow-up reminder cards increased uptake. (North Carolina, Oklahoma, Utah, West Virginia)

Utah was able to demonstrate an increase in postpartum blood glucose screening; Rates of self-reported postpartum blood sugar testing increased by 35%, from a pre-intervention baseline of 35.8% in 2009 to a post-intervention outcome of 48.5% in 2010 (p<.05).
Lessons Learned

• Integrated team approach for GDM care and education resulted in a decreased time interval to achieve glucose control during pregnancy (7.3 weeks to 3.8 weeks) and an increase in reports of positive lifestyle behaviors.

• Modified EMR templates increased provider awareness of GDM screening and follow-up from prenatal through annual visits.

• Postpartum reminders enhance postpartum visits and glucose screening by 30-35%.

• Home visiting programs are strong resource for providing education/information for women with GDM during prenatal and postpartum periods.

• Lack of provider/patient recognition that GDM complications are not temporary medical problems is difficult to overcome for patient/provider action.

• Although, a consensus on diagnosis of GDM was determined at the National Institutes of Health (NIH) Consensus Conference to utilize the Carpenter and Coustan methodology, the American Congress of Obstetricians and Gynecologists (ACOG) providers working with high risk populations continue using the ADA criteria to insure compliance.

• All systems need greater opportunities/access for primary diabetes prevention programs.
NACDD/Women’s Health

NACDD’s Women Health Council and the Collaborative communicated and disseminated activities and products through their website and webinars.

http://www.chronicdisease.org/?page=00GDMHomePage

The website design utilizes a hub. The hub allows the website viewer to click on the hexagon containing the desired information. The hub categories are:

- Gestational Diabetes Guidelines and Care Standards
- Partnerships
- Digital Library of Evidence Based Journal Articles and Literature
- Events and Webinars
- Resources and Tools
- Glossary of Terms

HUB 1  Gestational Diabetes Guidelines and Care Standards
Guidelines and Care Standards includes links to international, national state and organizational recommendations on screening, diagnosing, managing/treating and postpartum follow-up for women with Gestational Diabetes.

HUB 2  Resources and Tools
Resources and Tools include Gestational Diabetes clinical materials, tools, updates, links, and other information helpful for healthcare and public health practitioners. The topical areas are: General and Comprehensive; Preventive and Prenatal; Screening; Diagnosis; Treatment and Management; Postpartum; Educational and Quality Improvement Resources.

HUB 3  Digital Library of Evidence Based Journal Articles and Literature
The Digital Library contains links to Gestational Diabetes articles on the following topical areas: Prevention and Prenatal Care; Screening and Diagnosis; Care and Treatment; Postpartum; Reimbursement; Economic Impact; Health Disparities, and Public Health. This library also includes archived articles, articles published prior to 2008 and landmark articles.

HUB 4  Data
This Hub contains epidemiological information, data, and statistics related to gestational diabetes and related factors.

HUB 5  Partnerships
Partnerships include the Collaborative, the Network and links to other partners

HUB 6  Events and Webinars
The events hub is a link to webinars, conferences, meetings, and conference calls. Archived webinars are in this hub.
NACDD/Women’s Health Council

Accomplishments

**Increased collaboration with national partners**
- Served on policy building committees with United States Public Health Service (USPHS) Office on Women’s Health and Health Resources and Services Administration (HRSA)

- Served on data/surveillance committees with Council of State and Territorial Epidemiologists (CSTE), CDC and Association of Maternal & Child Health Programs (AMCHP)

- Shared initiative processes and accomplishments with Sweet Success and International Study Group on Pregnancy and Diabetes

**Increased knowledge on Gestational Diabetes**
- Building of a Gestational Diabetes website

- Developing a Gestational Diabetes Network of over 700 interested participants and produced 12 webinars

- Peer-reviewed articles related to Initiative

Outcomes

- States generated partner contribution of $5.50 per every dollar funded by NACDD/CDC

- Tribal organizations generated $1.00 for every dollar funded by NACDD/CDC

- Increased visibility with an GDM Interactive Website and a National Network on Professional Education

- Gestational Diabetes now included as a 2014 CSTE/Chronic Disease Indicator and in the AMCHP Maternal Child Health Indicators
Recommendations

• Develop a task force of national partners to focus on addressing the gaps in GDM provider knowledge and practice

• Assist state chronic disease programs to recognize that Gestational Diabetes is a pre-diabetes state and women and their offspring are the population with a greater risk for type 2 diabetes

• Develop innovative technologies that address patient education messaging to improve health literacy about women’s health throughout the lifecourse with special emphasis on Gestational Diabetes and Pre-Eclampsia

• Revisit the guidance and maternal worksheet for birth certificates as developed by National Center on Health Statistics to improve accuracy of documenting GDM prevalence – suggest adopting the Utah’s guidance and worksheet

• Assist Epidemiology and Statistics Departments in partnering with their maternal child health and chronic disease programs for better use of data sources and developing partnerships with external data sources for the collection, analysis and use of their data

• Improved and accurate data can lead to improved quality and comprehensive care for women with GDM
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1. Gregg, E, Sood, M; The Lancet Diabetes & Endocrinology, online Aug. 13, 2014


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