



Last revised: Fall 2013

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The NYC IUD Taskforce aims to ensure that everyone has access to a full range of contraceptive methods. The Taskforce seeks to address the systemic barriers (financial, institutional, legal, and educational) that may limit knowledge, awareness, access, and use of long-acting reversible contraceptive methods (LARCs), specifically IUDs and implants. LARCs are highly effective and safe contraception options that can be removed when no longer desired. More than 50 medical providers, educators, administrators, public health professionals, reproductive health advocates, and researchers from more than 25 New York City-based organizations currently serve on the IUD Taskforce. The IUD Taskforce's central activities are concentrated in the Taskforce workgroups, comprised of voluntary members that meet regularly.

A primary function of the Data & Monitoring Workgroup of the New York City IUD Taskforce is the identification and review of available literature and datasets on IUD use in New York City and nationally. The Data & Monitoring Workgroup is comprised of researchers, epidemiologists, information technology experts, public health practitioners and health care providers from organizations including Public Health Solutions, the New York City Department of Health and Health Hygiene and its Primary Care Information Project, the Guttmacher Institute, and Planned Parenthood of New York City, among others.

Like New York City, other cities, states, or regions may be interested in monitoring the use of IUDs. This review was conducted between January – August 2013, through key informant interviews, review of the literature and online queries. Here, we have identified best practices for developing and maintaining an IUD-related monitoring system. We then describe currently available datasets, their underlying metrics, and the limitations of each.

BEST PRACTICES FOR DEVELOPING AND MAINTAINING A MONITORING SYSTEM

As indicated by the limitations outlined below, no data or monitoring system is perfect. The Taskforce has identified some best practices that, if incorporated by medical administrators and practitioners, can improve our ability to monitor the use of IUDs and other long-acting reversible contraceptives (LARCs).

- Institutionalize and standardize data collection and monitoring to ensure stability over time and location
- Create specific response options for surveys by: separating IUD from implant and other effective methods; as well as separate categories for copper-containing and Levonorgestrel Intrauterine Systems (IUS).
- Reasons for removal should be recorded using closed-ended lists. Develop data systems to monitor metrics beyond insertions and removals, such as continuation or duration of use, as well as expulsion and reinsertion.
- Include modules and metrics measuring use of long-acting reversible contraceptive methods in existing survey systems.
- Consistently use codes within medical claims data to facilitate the monitoring of prevalence of long-acting reversible contraception (e.g. surveillance codes).

I. NATIONAL & LOCAL POPULATION-BASED SURVEYS

National Survey of Family Growth (NSFG)

Sample description: The National Survey of Family Growth (NSFG) is designed and administered by the National Center for Health Statistics (NCHS). The NSFG has been conducted since 1973. The current Cycle of the NSFG, covering the years 2006-2010, includes 12,279 women age 15-44. The sample is weighted to be nationally representative; black and Hispanic women and women age 15-24 are oversampled.

Metrics: Ever use of the IUD. Use of the IUD the first time had intercourse with a male. Current use of IUD. Where obtained IUD (if currently using).

Limitations: Does not distinguish between copper and LNG-IUS. The sample is nationally representative; data cannot be assessed at lower levels. No geographic information is provided in the publicly available dataset. A contextual file with geographic and other potentially identifiable information is available through the NCHS Research Data Center.

Available at: http://www.cdc.gov/nchs/nsfg/nsfg_2006_2010_puf.htm

Prenatal Risk Assessment Monitoring System (PRAMS)

Sample description: PRAMS, the Pregnancy Risk Assessment Monitoring System, is a surveillance project of the Centers for Disease Control and Prevention (CDC) and state health departments. PRAMS collects state-specific, population-based data on maternal attitudes and experiences before, during, and shortly after pregnancy. Telephone and mail-based surveys are conducted among women who have given birth to a live-born infant, in 40 states and New York City (as well as 6 states not currently conducting surveys). Data were first collected in 1987. Each participating state samples between 1,300 and 3,400 women per year.

Metrics: National and state/city-specific data are available; an application for data use must be submitted. Starting with Phase 7 (births May 2012 and later), current prevalence of IUD use among postpartum women will be available.

Limitations: Phase 7 data are not available yet. Before 2012, respondents were only asked about any contraceptive use (“Are you or your husband or partner doing anything now to keep from getting pregnant? Some things people do to keep from getting pregnant include not having sex at certain times [natural family planning or rhythm] or withdrawal, and using birth control methods such as the pill, condoms, vaginal ring, IUD, having their tubes tied, or their partner having a vasectomy.”)

Available at: <http://www.cdc.gov/prams/Researchers.htm>

Youth Risk Behavior Surveillance Survey (YRBSS)

Sample description: The YRBSS is a national school-based survey conducted by the CDC, as well as 47 state surveys, six territory surveys, two tribal government surveys, and 22 local surveys. The YRBSS samples students in grades 9–12, and is conducted in alternating years.

Metrics: Contraceptive method use at last sex. State and local data are available. Data are available online from 1991 through 2011. Data from male and female respondents.

Limitations: The most recent cycle available (2011) has a response option that does not separate IUD from other effective contraceptive methods: “Depo-Provera [or any injectable birth control], Nuva Ring [or any birth control ring], Implanon [or any implant], or any IUD.” The 2013 cycle will have a response option combining IUDs and implants. Contraceptive method use is only asked if respondent reports any sexual activity in the last 3 months; method use therefore not available for students who have ever been sexually active but not recently. Surveying is school-based; youth who are not in school are not included in the sample.

Available at: <http://www.cdc.gov/HealthyYouth/yrbs/index.htm>

Behavioral Risk Factor Surveillance System (BRFSS)

Sample description: The BRFSS uses telephone (landline and cell phone) surveys to collect state data health-related risk behaviors, chronic health conditions, and use of preventive services among US adults. BRFSS completes more than 400,000 adult interviews each year, making it the largest continuously conducted health survey system in the world.

Available metrics: The family planning module questionnaire in 2011 includes a question about IUD use at last sex. Females age 44 and younger who are not pregnant and who have not had a hysterectomy and males age 59 and younger are asked, “What did you or your husband/partner do the last time you had sex to keep you from getting pregnant?” The response options separate copper-containing IUDs from LNG-IUS, and include a response option for IUD of unknown type. Family planning module data are available as early as 1998.

Limitation: The family planning module is optional for states, so data are only available in states that administer the family planning module in a given year. In 2010, only 5 states used the module: Delaware, Florida, Kentucky, Mississippi, Montana. No states administered the family planning module in 2011. The wording of family planning questions is not always consistent from year to year, limiting ability to track indicators over time.

Available at: <http://www.cdc.gov/brfss/questionnaires.htm>

New York City Community Health Survey

Sample description: The New York City Community Health Survey is a cross-sectional telephone (landline and cell phone) survey, sampling approximately 10,000 adults in the five boroughs of New York City. The survey is based on the BRFSS.

Available metrics: Starting in 2013, contraceptive use at last sex will be collected. One response option is available, combining IUD and contraceptive implant.

Limitations: Data are available for online query going back to 2002, but data on method used at last sex are not available for previous years.

Available at: <http://www.nyc.gov/html/doh/html/data/survey.shtml>

II. PROVIDER-BASED DATASETS

Family Planning Annual Report (FPAR)

Sample description: The FPAR is an annual, uniform reporting source for all Title X family planning services grantees. In 2011, the FPAR included data from 49 state and local health departments and 42 nonprofit family planning agencies who served more than 5 million users through 4,382 service sites. In addition to the 50 states, FPAR includes data from 8 U.S. territories and jurisdictions.

Metrics: Current use of IUD (adopted or continued use at exit from their last encounter in the reporting period). Data from male and female family planning visitors. Aggregated data from 2003 through 2011 are available online. Regional data may be available by contacting Title X Regional Coordinators.

Limitations: Does not distinguish between copper and LNG-IUS. Does not distinguish between IUDs newly inserted at the visit and IUDs in place at the visit. Denominator is women who sought care for family planning services at Title X services, and is not generalizable to women who did not seek services.

Available at: <http://www.hhs.gov/opa/title-x-family-planning/research-and-data/fp-annual-reports/index.html>

Other Possible Provider Data Sources:

- Public health provider networks such as Departments of Health, public school based health center networks, and Federally Qualified Health Centers (FQHCs).
- Private for-profit insurance companies and networks.
- Private not-for-profit provider networks such as Planned Parenthood Federation and/or affiliates.

III. PAYOR-BASED DATA SOURCES

Medicaid Databases

Sample description: Data are available for all states and the District of Columbia beginning with calendar year 1999.

Available metrics: Female enrollment, the number of females who are currently sexually active, number of contraceptive prescriptions (including LARC) filled, and number of women with prescriptions filled.

Limitations: Dataset is only available through subscription.

Available at: <http://www.cms.gov/Research-Statistics-Data-and-Systems/Computer-Data-and-Systems/MedicaidDataSourcesGenInfo/MSIS-Mart-Home.html>

Health Care Cost Institute

Sample description: The Institute has compiled a comprehensive national claims database with information on health care utilization and costs for claims in the largest private insurance networks in the US (Aetna, Humana, Kaiser Permanente, and UnitedHealthcare), representing 40% of the privately insured population in the US. The database includes more than 5 billion medical claim records from 2000 to 2013.

Available metrics: Medical claims data classified by ICD-9 diagnosis and CPT procedure codes, including insertion, surveillance, and removals. Detailed information on diagnosis and procedure codes specific to long-acting reversible contraception has been developed by the American College of Obstetrics & Gynecology (ACOG):

http://www.acog.org/About_ACOG/ACOG_Departments/Long_Acting_Reversible_Contraception/~media/Departments/LARC/LARCQuickCodingGuide.pdf

Limitations: Includes only metrics captured by medical claims data. IUD surveillance codes may not be used consistently. Currently includes only private insurance networks; Medicaid data may be available in later years. Data are not accessible online; independent researchers who meet appropriate qualifications can apply for access to the data to perform specific research projects.

Available at: <http://www.healthcostinstitute.org/methodology>

Explore IUD related resources for researchers at:

http://www.iudtaskforce.org/resources_and_tools/researchers

For more information, please visit our website: IUDTaskforce.org

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