

Massachusetts Uses Linked Data to Drive Education on Assisted Reproductive Technology and Reduce Adverse Birth Outcomes

Through its participation in CDC's States Monitoring Assisted Reproductive Technology Collaborative, the Massachusetts Department of Public Health is linking datasets and leveraging its findings to promote single embryo transfers and reduce high-risk pregnancies with multiples.

In 2013, Massachusetts had one of the country's [highest](#) rates of live births from assisted reproductive technology (ART) at 4.8 percent, while the national average was 1.6 percent. As a result, Massachusetts had the nation's highest rate of ART treatments contributing to the births of multiples at 35.7 percent, versus 18.7 percent nationwide. Additionally, CDC [found](#) that in 2011, ART contributed to 15 to 17 percent of the state's low and very low birth weight infants and 13 to 17 percent of the state's preterm and very preterm births.

CDC [defines](#) ART as fertility treatments in which a provider handles both the sperm and eggs, including [in vitro fertilization \(IVF\)](#). When used responsibly, IVF and other ART procedures can help patients have the family they long for. However, inserting multiple embryos into a patient's uterus increases the patient's odds of having multiple infants, such as twins or higher order multiples.

Pregnancies with multiples are [risky](#) for the babies and their mothers. Twins are [five times](#) more likely to be admitted to the neonatal intensive care unit than singletons. They are also more likely to be stillborn, die shortly after birth, and have heart, brain, or face birth defects. Mothers of twins are [twice](#) as likely to have preeclampsia as mothers of singletons, and half of all mothers of triplets develop preeclampsia.

For some IVF patients and their infants, transferring one high-quality embryo is a healthier option than transferring multiple embryos. For qualified patients—such as those who age 37 and under who haven't done IVF, undergone only one previous IVF cycle, or had a previous live birth—[elective single embryo transfer \(eSET\)](#) with one fresh embryo and one thawed embryo has been shown to have the same cumulative pregnancy success rate as transferring multiple embryos, but with fewer risks.

Massachusetts is one of [few states](#) that [mandate](#) insurance coverage for fertility treatments, creating unique opportunities to investigate health risks related to ART and promote eSET among IVF patients.

Steps Taken:

- Massachusetts' work on ART began in the late 1990s when a former Massachusetts Department of Public Health (MADPH) employee noticed that the state's rates of preterm birth were rising even though other perinatal birth outcomes were improving.

- In 2013, Massachusetts had one of nation's highest rates of births resulting from ART at 4.8 percent.
- The state health department is working with CDC to link datasets related to ART, reduce multiple embryo transfers, and improve birth outcomes.

- To explore the links between ART, multiples, and poor birth outcomes, MADPH and CDC launched a [pilot linkage project](#) in 2001 to connect ART and health outcomes data. The pilot project's goals were to (1) create an ART population-based dataset using conception and delivery information from mothers who underwent ART and their infants, and (2) compare it with similar data from mothers and infants who did not undergo ART.
- The pilot project led to the CDC Division of Reproductive Health creating the [States Monitoring Assisted Reproductive Technology \(SMART\)](#) Collaborative, which promotes state-based ART surveillance to help the states evaluate maternal and perinatal outcomes and programs. In Massachusetts, SMART connects state data with ART surveillance data for infants born to female residents who received treatment at ART clinics in Massachusetts and nearby states.
- To support state public health leadership on ART issues, MADPH received a \$35,000 sub-award from ASTHO, a SMART Collaborative partner.
- The Massachusetts SMART data showed the magnitude of ART's contribution to multiples and poor birth outcomes in the state, says Dana Bernson, principal investigator for the Massachusetts SMART project.
- In 2013, MADPH held a kick-off meeting to reintroduce itself to clinicians in the field, talk about SMART, and breakdown communication barriers, and invited all of the clinics in the region. MADPH staff also used the meeting as an opportunity to solicit clinicians' feedback on how they were using SMART data and their experiences with eSET.
- After the kick off, MADPH held follow-up conference calls with clinics to determine next steps. In 2015, Bernson held individual meetings with six clinics, where she gave presentations on SMART's history, the links between ART and poor birth outcomes, and the benefits of eSET. MADPH staff thought initially that they would have to educate clinicians about the risks associated with multiple embryo transfers. Instead, it found that the physicians already knew the risks, but felt they had few options to promote eSET among their patients.
- During their conversations with clinicians, MADPH staff were surprised to learn that many IVF patients fall into an infertility treatment insurance coverage gap, despite the state's reputation for having the gold-standard coverage mandate. Clinicians reported that 25 to 50 percent of their IVF patients were paying for at least some of their treatment out of pocket. Reasons for the coverage gap include that about 50 percent of Massachusetts companies self-insure and therefore, are exempt from the mandate, as are public insurers. Moreover, some Massachusetts residents are employed in neighboring states and have out-of-state insurance.
- Several clinicians said another challenge was that some patients were less concerned about maternal complications than they were with potential complications for their children. Some patients were willing to risk their own health to get pregnant, but were more cautious regarding the health of their potential baby. However, they were sometimes willing to accept some birth complications if it meant they would eventually take home a healthy baby.
- Recognizing the need for effective, standardized patient education materials, MADPH conducted a pre-survey to find out what education materials clinicians were using regarding multiples and eSET and what they believed would be helpful. MADPH then worked with CDC to develop new materials, shared them with clinicians, and revised them based on the clinicians' feedback.
- Additionally, some clinics had already created their own successful, comprehensive education programs. Baystate Health, a nonprofit healthcare system that offers infertility services, holds mandatory group education sessions on eSET and health risks with multiples for its prospective patients. The hour-and-a-half group session includes presentations from a physician and

embryologist, and uses information from the American Congress of Obstetricians and Gynecologists on birth outcomes. After the class, physicians have one-on-one counseling sessions with patients to follow up. As a result, Baystate Health IVF Medical Director Kelly Lynch says that a vast majority of patients choose eSET because they know the risks.

- A next step for the Massachusetts SMART project is to engage with insurance companies to promote eSET. Some insurers in the state have already shown leadership in this area. In September 2014, Blue Cross Blue Shield of Massachusetts (BlueCross MA) [announced](#) that it was updating its infertility diagnosis and treatment medical policy, effective October 2014.
 - For enrollees younger than 35 years old undergoing IVF, BlueCross MA covers only the transfer of a single embryo for the patient's first two IVF cycles.
 - For enrollees between the ages of 35 and 37, it covers the transfer of a single embryo for the patient's first IVF cycle and then removes the restriction for subsequent covered cycles.
- BlueCross MA also encourages physicians to share its educational publication, *For the Health of Mother and Baby: Single-Embryo Transfer*, about eSET and why multiples gestation can be dangerous for mothers and babies. Bernson noted that insurance companies may want to promote eSET because it reduces costs from poor birth outcomes, such as long-term neonatal intensive care unit stays.
- MADPH staff have also started a SMART initiative in which they will use the state's all-payer claims data base to examine medical and pharmacy data and determine how multiples rates are linked to non-ART fertility treatments, such as timed intercourse with ovulatory stimulant drugs and intrauterine insemination (IUI).

Results:

- MADPH's innovative fifteen-year collaboration with CDC on ART issues has resulted in a rich dataset for the state that [links](#) birth certificate files, infant death records, maternal death records, fetal death records, and birth defects records with ART surveillance data.
- MADPH's partnerships with area fertility clinics led to the department and CDC creating standardized patient education materials, *Having Healthy Babies One at a Time*. The two-pager "[Why are we worried about twin pregnancies?](#)" covers risks associated with multiples and statistics showing that transferring one fresh embryo during a first IVF cycle, followed by a single thawed embryo during a second cycle if necessary, offers patients the best chance at a positive perinatal outcome. The one-pager "[How many embryos should I transfer to have one baby?](#)" breaks down a good eSET candidate's likelihood of having a singleton after transferring one embryo at a time and compares the rates to those of double embryo transfers.

Lessons Learned:

- SMART projects have the power to uncover birth population trends that birth certificate data alone can't show. For example, birth certificate data won't reveal long-term outcomes, but linking birth certificate data, fertility clinic records, and death records can expose the true magnitude of an issue.
- State and territorial health departments can provide literature and leadership on eSET that make an impact on patients. Patients who receive materials on the benefits of eSET and

thorough counseling from their fertility doctors are more likely to choose eSET, whereas patients who receive more superficial education are more likely to want to transfer multiple embryos, according to Aaron Styer, associate director of the Basic Science Research Program for the Reproductive Endocrinology and Infertility Fellowship at Massachusetts General Hospital.

- Don't underestimate the scope of a SMART project, and cultivate a champion in leadership at your department. Linking datasets is often complex, particularly if you haven't done it before. It's challenging, important work that needs leadership support.
- Establish common goals with partners and determine what each party can contribute, whether it's in education, technology, or leadership. For example, health departments can't interview ART patients due to privacy restrictions, but clinicians can bridge the information gap. In Massachusetts, the clinician partners offered valuable insights into their patients' experiences and how best to communicate with them.
- State and territorial health departments can serve as an intermediary between clinicians and SMART. Clinics in Massachusetts can now access SMART data for their own research and to drive their own policy changes. Being able to give something back to the clinics helps strengthen their partnerships with MADPH, says Bernson.

This story was made possible through funding from CDC's Building Capacity in Maternal and Child Health Programs (Cooperative Agreement 1U38OT000161). ASTHO is grateful for its support.

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