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RE: CDC, Assisted Reproductive Technology (ART) Program Reporting System

Dear CDC:

Thank you for the opportunity to comment on the Assisted Reproductive Technology (ART) Program Reporting System. This comment responds to the identified issue of "enhanc[ing] the quality, utility, and clarity of the information to be collected."

As professors and social scientists researching assisted reproduction, we utilize the Centers for Disease Control and Prevention's *Assisted Reproductive Technology Fertility Clinic and National Summary Report* that is generated via the ART Program Reporting System in our research. This report and the available datasets providing the underlying data are a primary data source for statistics on ART and for understanding the scope and practice of ART in the U.S. We write to express our support for continued data collection. Continued collection and reporting of these data remain vitally important. Specifically, these data are the only high-quality, publicly-available data on ART success rates and births in the U.S. Although information on ART-use is collected on the U.S. birth certificate, several studies have shown that birth certificate data underreports ART births (e.g., Cohen et al. 2014; Moaddab et al. 2016; Thoma et al. 2014; Tierney and Cai 2019). Further, the vital statistics datasets are often difficult for the general public to access due to the size of the data files, which necessitates the use of specialized software. In addition, based on historical studies (Stephen et al. 2016), demographic projections (Tierney 2022), and ongoing delays to first births (e.g., Osterman et al. 2024), we believe demand for ART will only increase. Therefore, continued collection and reporting on these data is necessary to both inform patient-clients and enhance population-level research on ART.

We would like to communicate our appreciation for the improvements made over the years to data collection efforts and the presentation of the generated data in the ART Fertility Clinic and National Summary Report. This includes the change begun with the 2021 report of including numbers of patients receiving ART treatments, in addition to the number of ART cycles. We appreciate the attention to this data collection and would like to make five specific suggestions for continued improvement.

1) While demographic data are collected, expanding the patient demographic data that are made available and easily accessible in the national summary report and dataset would not only assist social scientists studying ART but would help to provide more transparent data to patient-clients about ART accessibility. We make the following specific recommendations related to demographic data collection/reporting:
    a. *Improvements to Race/Ethnicity Reporting* – given the well-documented disparities in ART access and outcomes by racial/ethnic groups, efforts to address the known quality issues in the reporting of race/ethnicity (as reported by Wellons et al. 2012) is needed both for patient-clients searching for care and to improve research on these inequalities at the population-level. Furthermore, reporting easily accessible demographic information on gestational carriers would provide much-needed data for researchers.
    b. *Improvements to Age Reporting*— First, in the reports, most data charts are displayed only by age groups, which obscures the overall rates. Thus, we believe adding a summary of aggregated data in the consumer-facing reports would be useful . At the same time, datasets provided to researchers, or geared toward clinicians, should include more detailed information of outcomes by age. More detailed age reporting would be valuable to consumers as they seek to make informed medical decisions, and to clinicians counseling patients. Therefore, reporting of these data by single-year of age or with more clearly bounded age groups would enhance their utility. For example, many outcomes are reported for individuals under 35 and over 40. However, for quantitative research, such "unbounded" numbers require researchers to make assumptions about the population at-risk. Importantly, we believe that such detailed age data should only be reported at the national-level to help safeguard individuals' privacy.
    c. *Addition of Indicators of Socioeconomic Status* —another area of inequality in ART utilization and outcomes is related to socioeconomic status. As policy-contexts for mandated coverage continue to change, information on social class (such as income, educational attainment, or even insurance or payment type) would represent a critical expansion in the ability of researchers to understand access to ART care and inequalities in ART by socioeconomic status.
2) Certain language choices could be updated, specifically: the term "gender" is used in reports when referring to "sex" and the term "people" could replace "women" in order to be more gender inclusive.

3) While an explanation for the use of the term cycle is provided, referring to procedures as cycles may prove confusing for readers of the national reports, especially for patient-clients.

4) The percentages provided in the tables in the National and Clinic reports (e.g., the percentage of cycles for fertility preservation by patient age in the "Characteristics of ART Cycles" section) are easily interpretable and of use for patient-clients. However, for the research-oriented dataset, we would strongly advise directly reporting the underlying numbers (e.g., number of cycles for fertility preservation in each age group). Such an adjustment would allow researchers to transparently create their own measures without the need for "back-calculations," which introduces error.

5) Starting with the 2019 data on the Archived ART website (https://www.cdc.gov/art/reports/archive.html), the presentation of clinic data on the EXCEL spreadsheet for each year changed, such as the "Clinic Table Data Records" no longer being available. The consistency of those data from 1995 forward is helpful for researchers studying changes and trends in ART-providing clinics. We suggest reintroducing the Clinic Table Data Records in the archived data.

In summary, the ART data collection and high-quality reports made available via the CDC are vital for researchers studying assisted reproduction in the U.S. and useful for patient-clients and those providing services and support to them. Our comments here reflect suggestions for improvement based on our experiences using the data. Thank you for the opportunity to make comments.

Sincerely,

Dr. Tierney, Dr. Jacobson, Dr. Leyser-Whalen

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