Creating the Fetal and Infant Mortality Review (FIMR) de-identified case summary

For each case of fetal or infant death to be reviewed, information is collected from a variety of sources, which may include physician and hospital records along with those from home visits and relevant community program records. Information is also obtained in an interview with the family. All identifying information (i.e., names of families, providers, institutions) should be removed and an anonymous summary of the case is presented to the case review team (CRT). Only the case abstractor and the maternal interviewer will know the identities of the families and providers. As much as possible, the goal is to remove all identifiers from the case narrative summary so that those involved in the review will not recognize the case.

The Privacy Rule defines “Individually identifiable health information” as information, including demographic data, that relates to:

- the individual’s past, present or future physical or mental health or condition
- the provision of health care to the individual, or
- the past, present, or future payment for the provision of health care to the individual and that identifies the individual, or for which there is a reasonable basis to believe it can be used to identify the individual. Individually identifiable health information includes many common identifiers (e.g., name, address, birth date, Social Security Number).

All FIMR programs need to collect and summarize enough information to be able to relate the story of each case from a systems perspective, including but not limited to factors such as access, barriers, patient education, psychosocial assessment, lifestyle choices, coordination of services, and discharge planning. Presenting this information to the CRT in a de-identified and anonymous way can be challenging. At a minimum, the following information should be redacted from the case summary reports presented at FIMR team meetings:

- Names: All names of the child, mother, medical and social service providers.
- Dates: All dates of service, birth or death. The year can be maintained.
- Location: All address information, except zip codes, should be redacted. If the population is small, zip codes may be withheld.
- Contact information: All telephone and fax numbers, email addresses and physical addresses.
- Certificate/license numbers: All birth, death, marriage and other license or certificate numbers.

A few tips and examples of strategies can be seen in the table below.

<table>
<thead>
<tr>
<th>Identified</th>
<th>De-identified</th>
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<tbody>
<tr>
<td>Jane Smith entered prenatal care on 6/15/2019 at the Covenant Family Care Clinic and saw Dr. Jones for 12 visits.</td>
<td>The client was a 25-year old G1 P0 mom who entered prenatal care at 8 weeks gestation. Her care was provided by an OB/GYN physician at a large federally qualified health center and she completed 12 visits.</td>
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<td>Mary Jones had an ultrasound on 6/10/19 that confirmed the baby was between 15- and 16-weeks gestation.</td>
<td>Client had an ultrasound appointment at 16 weeks gestation for to confirm dating.</td>
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Susan White had 4 visits with Dr. Johnson on 1/8/19, 2/10/19, 4/6/19, and 6/8/19.

Client was seen in consultation by a maternal fetal medicine specialist for four visits, at 32, 33, 35, and 37 weeks gestation.

When it will not compromise the flow and chronology of events, leave the specific dates out. Dates and times for important events, such as presentation at hospital admission, estimated date of confinement, rupture of membranes, delivery, transfer and discharge can all be presented by using the month, year, and gestation. For example, when presenting previous pregnancy outcomes:

- November 2019: pregnancy under review, infant born at 28 weeks gestation
- August 2017: live born term infant, 39 weeks gestation
- March 2015: 12-week miscarriage

Ultimately, the case summary tells the story of one fetal or infant death to the team. It is a blend of the clinical/medical information and the parent/family interview. Many programs present the case information as a chronology of events. In order to keep the case succinct, use key points and summarizations. For example, a systems review (respiratory, cardiac, neurologic, gastrointestinal, etc.) may be helpful in a case of an infant with a lengthy NICU stay. While styles may vary according to team preference, a third-party narrative is generally used. Objectivity is key! Stick to the know details of the case leaving off opinions and conjecture. It is important to present conflicting information, as it may illustrate provider to patient communication challenges. Finally, noting when information is not available may also illuminate systems or documentation issues.

Detailed information on creating the de-identified case summary can be found in the FIMR 101 Module found on the NCFRP web site: https://mediasite.mihealth.org/Mediasite/Catalog/catalogs/cnpi

Additional Resources: US Department of Health and Human Services, Guidance Regarding Methods for De-identification of Protected Health Information in Accordance with the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule

https://www.hhs.gov/hipaa/for-professionals/privacy/special-topics/de-identification/index.html#protected