Abstracting Data for FIMR Research

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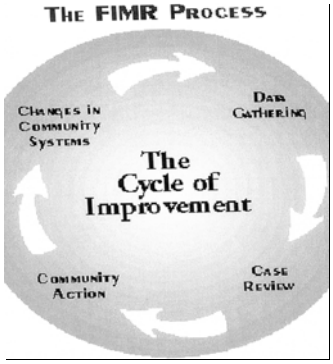
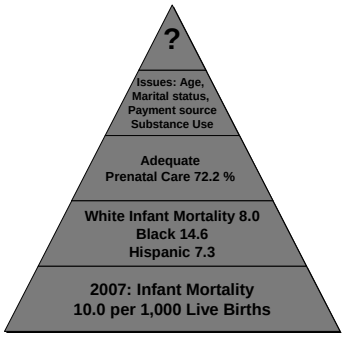
Introduction

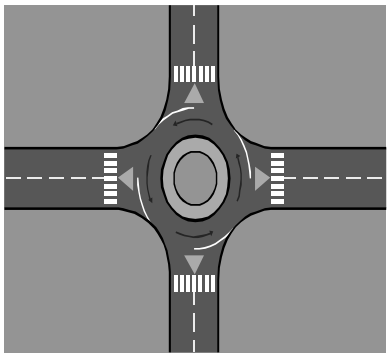
FIMR Process



FIMR Helps to Answer the Questions



Entering The FIMR Process



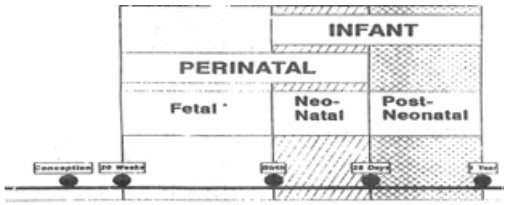
FIMR Staff

- **Project manager**
- **Abstractor**
- **Interviewer**
- **Secretary**
- **Data entry**
- **Data analysis**
- **Interventionalist**
- **Media/PR**
- **Fiscal manager**

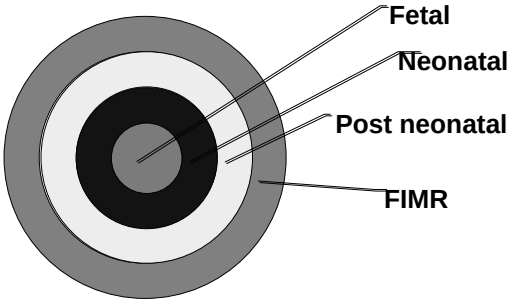
Starting the Process

- Community picks focus
- Identify data sources
- Identify tools
- Identify FIMR abstractor/interviewer
- Identify legal information

Community Picks the Focus



FIMR Is Comprehensive and Embraces All the Issues



Identification of Cases

- Fetal/Neonatal/Postneonatal
- Timing issues
  - Retrospective/current
- How many?
  - All in small, random in large
- Be sure to represents community, not an individual's choice

FIMR Data Sources

- Vital statistics
- Maternal interviews
- Medical records
- Social services

Vital Statistics

- STRENGTHS
  - Traditional/well established
  - Availability
  - Community specific/opulation based data
  - Helps with FIMR focus
- WEAKNESS
  - Limitations
  - Accuracy

Medical Records

- **STRENGTHS**
  - **Availability**
  - **Glimpse system care**
  - **Fetal, neonatal and maternal information**
  - **In patient and outpatient records**
- **WEAKNESS**
  - **Technical**
  - **Lack psychosocial data**
  - **Time consuming**
  - **Poor imaging on computerized records**

Maternal Interview

- **STRENGTHS**
  - **Community voice**
  - **Powerful information**
  - **Consumer perspective**
  - **Bereavement follow up and referrals**
  - **Cultural focus**
- **WEAKNESSES**
  - **Can be hard to locate**
  - **Conflicting information**

Social Service Records

- **Referrals**
- **Support services**
- **Education**
- **WIC**
- **Case management**
- **Other**

NFIMR Forms

- **Comprehensive**
- **Multi-system**
- **Free**
- **Revised**
- **History of use**

NFIMR Forms

Type*	Name	Pages	# Question
I	Ambulatory Infant	6	24+
F/I	Autopsy	1	3
F/I	Fetal/Infant Death Certificate	1	10
F/I	Labor and Delivery	10	38
F/I	Mother Interview	24+	134
I	Home Interview/Baby Health at Home	5	25
I	Newborn Assessment	4	14
I	Newborn Intensive Care	7	23
I	Pediatric ER and Hospitalization	4	18
F/I	Placental	2	6
F/I	Prenatal	13	42
F/I	Referral for Services	1	1

F=fetal
I=infant

78

338

Organize Cases:
Fetal: Autopsy, death certificate, labor and delivery, interview, Placental, prenat referral

Infant: ambulatory, autopsy, death certificate, interview, interview infant health newborn assessment, NICU, pediatric ER, placental, prenatal, referrals

Abstractor/Interviewer

- **Flexible**
- **Knowledge base**
- **Transportation**
- **Computer and people skills**
- **Unbiased storyteller**

FIMR Legal Issues

- Know your statutes/immunity
- Institutional Review Board (IRB)
- Health Insurance Portability and Accountability Act (HIPAA)
- Confidentiality protocols
- Accessing records/limitations
- Storing information
- Child abuse reporting laws

HIPAA

- Health Insurance Portability and Accountability Act (HIPAA) of 1996: to protect privacy and security of exchange of health information
- See sample letters in ***FIMR: HIPAA Privacy Regulations***

Confidentiality is Key

Abstraction Methodology

- Organization of cases
- Accessing sources
- Communication skills
- Approach to barriers

Early Organization

- Assemble abstracting materials
  - Fetal/infant packet
  - Case identifiers
  - Legal forms
- Abstracting supplies
  - Pens/pencils
  - Extra abstraction forms

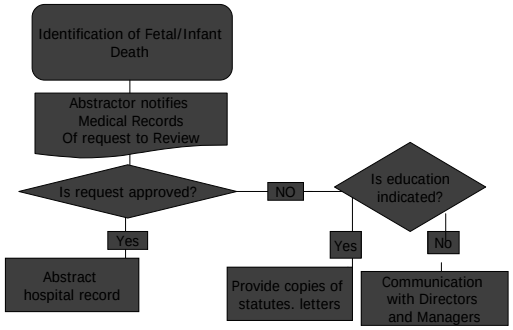
Early Organization

- Make a list of hospitals and contact persons/phone and secure fax numbers

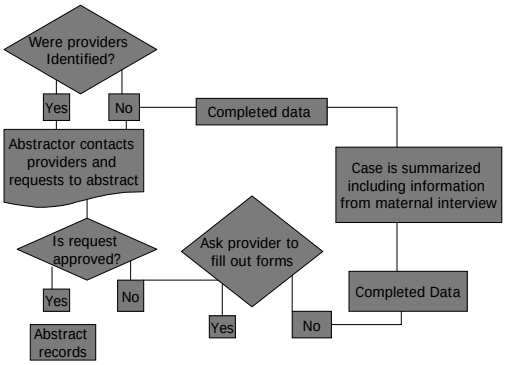
Access

- **(ak'.ses) n. a coming to the means or way of approach: admission; entrance; attack; fit.**

Abstraction Pathways



Abstraction Pathways



Additional Information

- **Details back of forms**
- **Treatments and follow up**
- **Answer timing questions**
- **Supportive lab information**
- **CRT helps to evolve type info needed**

Abstracting Tips

- **Chronological order events**
- **Don't put in your opinion**
- **OK to present conflicting information**
- **Notation on forms if didn't find information**
- **Keep forms de-identified**

Basic Abstracting Rule

"If the information about a question is not in the chart it was NOT done." – (NFIMR)

Abstracting Barriers

- Provider refusal
- Lost records, incomplete misfiled
- Communication confusion
- Missing contact person
  - Always have a back up person
- Traveling

Communication Skills Important

- Not burn bridge
- Take time to be known
- Represent your project
- Refusal to participate due to many factors
- May join with time if decreased threat
- Have sensitivity to provider grief

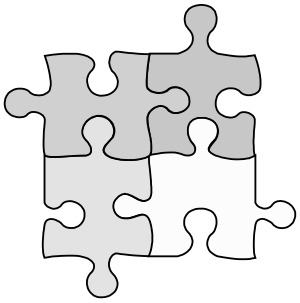
Abstractor Interventions

- Abstractor not to change system by self
- Key points
  - Confidentiality
  - Ethical decision: system vs. individual
- Omissions/clerical errors
- Suspected child abuse
- Copy records for others

"Laws" of the Abstractors

The distance you have to travel for a record is directly proportional to the length of your summary.
The incidence of phone calls to providers in inversely proportional to the success of your abstracting.
The greater past relationship you have with a provider, the less likely they will give you access to their records.
The record you abstract quickly is most likely to be the hardest to summarize.
The longer a case is discussed at a CRT meeting, the more certain it is the no one has the faintest idea of what happened.
The probably of crying is directly proportional to the number of case you have abstracted.
If you can't figure out what to do next in an abstractor pathway, call another abstractor. They may not have any idea either but you sure will feel better.
The 'success' of the project is directly proportional to the community's response.

Summarizing The Story



Summarizing The Story

- Medical/social and maternal interview
- De-identified
- Preserves mothers voice
- Caution what eliminate/not bias
- Consistent for CRT deliberation
- Types: narrative/bulleted/italics

CASE PRESENTATION #

Vital Statistic Infant Death Certificate Information:
Sex:
Cause of Death:
Lived:
Weight:
Weeks Gestation:
Mother: (age/race/ethnicity/education/marital status)
Previous Pregnancies:
Father: (age/race/ethnicity/education)
Prenatal Care: (began/#visits)
Weight Gain:
Substance Use:

Case Summary Synopsis: (Information form the medical record)
The mother was (age, gravida, para, race/ethnicity, marital status, education, occupation). She entered prenatal care at---weeks at a (place) with care by (provider) with (# visits). Medical history was significant for:____. Prenatal history included: ___. Prenatal referrals included____. She delivered at a level /place at ___weeks gestation by ----delivery method. Apgars were ----, birth weight was----. The infant (was/was not discharged) on day ____. Infant complications included:____. Pediatric history was significant for _____. Pediatric referrals included_____. The infant died at (age) and the events before death included _____. An autopsy was/was not done. Findings included: _____Bereavement support to family was/ was not done.

FIMR Case #

MEDICAL RECORD	MATERNAL INTERVIEW
1. Medical: Mother **Prenatal Medical record:** Mother 7, **3, 4, 5, 6**, gravida 14, para **14** **Previous Pregnancies: 14 A, B, etc.** **LMP: 13 EDC: 13 A** by dates: **13 B** by sonogram **HIV:** 17 **Prenatal labs:** (Include blood type) 18. Results unremarkable except for: Treatment was _____. Repeat at ____ weeks noted. **Pre-existing medical problems: 25** **Medications: 24** **Problems developed: 26** **Nutrition: 29** **Pre-pregnancy Weight: 27** **Height: 28 B Identified nutritional factors: 30** **Gained: 28** by **28** weeks. **Body Mass Index:** **Nutritional referrals: 31** **Other testing/Procedures:** (include weeks done and any referrals) **38** **Hospitalizations: 42**	***1. Medical: Mother*** *She was E 1 and E 2 years old, was born E3, and is E4. She completed E6 and E7. She 13 Her baby was D1 and D1a&b. Prior to this pregnancy she was pregnant D 3, with D 4. D5.* *She was A1 weeks when she thought she might be pregnant. She was A2 when she was sure she was pregnant. She was A 20 with her care (Note: expand on issues if not satisfied). During her pregnancy she A 27. She took A34 special precautions to prevent preterm labor. (A35) She describes her health during her pregnancy as A 36. She was B 1 on a special diet. Her prepregnancy weight was B2, and she gained a total of B4 and she is B5 tall. She B8.*
Labor and Delivery Medical Record: **Hospital Level: 1** **Time: 2 Gestational Weeks:** (write in) **Reason for Admission:** (write in, include how long with symptoms of labor, what complaints and how arrived)	**Labor and Delivery: (Maternal Interview)** *She was C1. and C2. She delivered in C3 on C7. Her due date was A3. She describes her delivery as C4. She spent C 5 nights in the hospital. C 8 - 9 - 10 - 11.*
Medical Mother Continued Labor and Delivery Continued	*She says what happened is: Maternal Interview 1 page 11.*
Admission History: write in evaluation at admission, stage of labor, condition, include BP if has a history of hypertension, note any abnormalities. **Membranes: 3 - 4 - 5** **Monitoring:** Include information of initial fetal heart rate and also rate prior to delivery. **10 A-B** **Problems in labor and delivery: 11 Referrals: 18 - 20 Medications: 17** **Anesthesia: 17**	

CASE # NFIMR 2009 Fictitious

Vital Statistics Fetal Death Certificate
Sex: Male
Cause of Death: Intrauterine fetal demise
Weight: 8 pounds 7 ounces
Weeks Gestation: 40
Mother: 20. White, 12 years education, single
Previous Pregnancies: none
Father: 22, white, 12 years education
Prenatal Care: 1st month, 17 visits
Weight Gain: 25 pounds
Substance Use: none
Delivery: vaginal

CASE # NFIMR 2009 Fictitious

- **Cases summary synopsis: (information from medical record and interview)**
  - **The mother was 20, gravida 2 para 0010, single, 12 years education, homemaker**
  - **She entered prenatal care at 6 weeks at an OB private office with 17 visits**
  - **Medical history was significant for termination of pregnancy age 15**

CASE # NFIMR 2009 Fictitious

- **Prenatal history was significant for anemia treated with iron and multiple hospital ER visits for complaints spotting and discharge after 28 weeks**
- **Prenatal referrals to WIC and Healthy Start**
- **At 40 weeks she presented to a Level I hospital with contractions and complaints of abdominal pain**
- **Fetal demise was noted on ultrasound**

CASE # NFIMR 2009 Fictitious

- **Four hours after admission she had a vaginal delivery with small placental abruption noted**
- **Birth weight was 8 pounds 7 ounces**
- **An autopsy was requested but refused by family**
- **Day after delivery, mother left hospital against medical advice with her boyfriend**
- **Bereavement support was documented**

CASE # NFIMR 2009 Fictitious

- **Mother agreed to FIMR interview 8 weeks after delivery**
- **Interview took place at her parent's house**
- **She requested boyfriend never know of the interview**
- **During the interview she told nurse that he had threatened to harm her during her pregnancy and she was worried that was what "killed her baby"**

Medical Record

Medical: Mother

Prenatal Medical record:

- **Mother 20, white, USA, gravida 1 para 000**
- **Previous Pregnancies: none**
- **LMP: 10/10/06 EDC: 7/17/07 by dates,**
- **7/20/07 by sonogram at 12 weeks**
- **HIV: tested negative, pre and posttest counseling documented**
- **Prenatal Labs: A+, GC neg., Chlamydia neg., Rubella immune, Hep neg., urine culture neg. PAP wnl. Initial H/H 12/36.2**

Medical Record

- **Results unremarkable except for elevated GTT 146, 3 hour GTT wnl. Repeat H/H 9.8/30.2**
- **Treatment was Iron tabs bid. Repeat H/H 11/32.**
- **Pre existing medical problems: none**
- **Medications: PNV, Iron**
- **Problems developed: none**
- **Nutrition: assessment not documented**
- **Pre pregnancy Weight: 176**
- **Height: 5'4"**

Medical Record

- **Identified nutritional factors: none**
- **Gained: 40 pounds by 40 weeks.**
- **Body Mass Index: 30 (obese)**
- **Nutritional referrals: WIC**
- **Other testing/Procedures: HIV, urine C&S, 1 hour GTT at 30 weeks wnl, AFP 17 week's wnl.**
- **Prenatal Hospitalizations: Level I ER**

Maternal Interview

1. Medical: Mother

- **She was single, 20 years old, born in USA and is white. She completed 11 years of education and is attending night school for her GED. Her baby was a singlet. Prior to this pregnancy she had a termination at age 15 but her boyfriend and parents don't know.**

Maternal Interview

- **She was 4 weeks when she thought she might be pregnant. She was 6 weeks when she was sure she was pregnant. She was satisfied with her care. During her pregnancy she did not attend parenting or childbirth classes. Her boyfriend did not want her to go.**

Maternal Interview

- She took no special precautions to prevent preterm labor. She describes her health during her pregnancy as good but she said she always worried something would happen to her baby. The ending weeks of her pregnancy she was scared something was happening to the baby as her boyfriend kept threatening her. She went to the ER frequently to be checked.

Maternal Interview

- She was not on a special diet. Her pre pregnancy weight was 165, and she gained a total of 36 pounds and she is 5'4". She craved ice.

Caring For Self

Responses to FIMR

- Grief is normal initial response
  - For person
  - Family
  - Providers
- You may be sad about cases and want to discuss them

Responses to FIMR

- Remember confidentiality protocols
- Actions are healing part of the project
- FIMR has been a healing process for systems of care

You are Laying the Foundation

“The best preparation for tomorrow is to do today’s work superbly well.”
– Sir William Osler