



**Supplemental  
Online Content  
(SOC)**

**Women's Experiences with  
Severe Maternal Morbidity  
in New York City:  
A Qualitative Report**  
December 2020

This SOC includes detailed information on how the qualitative study component of the SMM Project was implemented. The document features resources that would allow researchers to replicate the research in other jurisdictions to better understand the implications of SMM in other communities.

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## Detailed Methodology

## **Hospital Recruitment**

The in-hospital recruitment occurred from November 2018 through December 2019. Eligible participants were identified during the childbirth hospitalization as those who had an intensive care unit (ICU) admission or at least four units of any blood product transfused during the delivery hospitalization period. In addition, eligible participants had to be comfortable completing an interview in English or Spanish, residents of one of the New York City boroughs, 18 years or older, and not hospitalized or severely ill at the time of scheduling the interview. Also, people were ineligible for the study if their child was dead, hospitalized, or severely ill at the time of scheduling the interview.

The process of identifying eligible participants differed between the two hospitals. Hospital 1 had a dedicated full-time staff member reviewing records daily to identify potential participants. Hospital 2 relied on providers, including residents, midwives, and physicians, to alert the part-time New York City Department of Health and Mental Hygiene (NYC Health Department) study personnel when there was an identified case meeting the eligibility criteria.

Eligible participants were first contacted by NYC Health Department study personnel prior to hospital discharge. This criterion was later amended, and eligible participants who were missed during their birth admission were able to be contacted within six weeks of discharge. Study personnel explained the study and asked eligible participants if they wanted to be included. If so, they were asked to complete a Permission to Contact Form (pp. 14–17). Potential participants who completed a Permission to Contact Form were contacted by a study interviewer 10–12 weeks after the hospital discharge to confirm their agreement to participate. This was an intentional and strategic decision by the study team to begin to build rapport between potential participants and the interviewer at the first point of contact. Interviewers contacted eligible participants via phone calls and text messages up to three times. If they were unreachable or they declined participation, they were removed from the list of potential participants. If they agreed to participate, interviewers scheduled the in-depth interview to take place at a quiet, private location chosen by the participant (e.g., home, community center, library, etc.).

## **Community Recruitment**

Over time, it became apparent that the intended sample size could not be attained solely through hospital recruitment, due in part to the rarity of severe maternal morbidity events and in part to the fact that fewer people than anticipated agreed to be interviewed. Therefore, a convenience sampling approach was added and employed simultaneously halfway through the Project. Recruitment flyers were placed at locations most likely frequented by new mothers (e.g., Special Supplemental Nutrition Program for Women, Infants, and Children [WIC] offices, laundromats, libraries, and neighborhood parks) in communities located near hospitals. Individuals self-identified and expressed interest in the study by calling the phone number on the flyer. During the phone call, they were screened to determine their eligibility. Individuals were then contacted to schedule an in-depth interview.

## Research Team

The research team consisted of the principal investigator, two research consultants, one analytic consultant, three interviewers, one data manager, one administrative manager, three hospital-based clinical case abstractors (two at Hospital 1 and one at Hospital 2), and three other research support staff. The members of the research team were selected based on their methodological expertise in qualitative research, including research design, data collection (particularly in-depth interviews), data analysis, and report writing. The research team had expertise in women's health, including midwifery, childbirth, doula care, and severe maternal morbidity, a life-threatening complication during childbirth delivery that results in significant short-term or long-term consequences to a woman's health (SMM), and maternal mortality, the death of a woman while pregnant or within 42 days after the end of pregnancy from any cause related to or aggravated by the pregnancy or its management (MM).

## Training of Interviewers

Study consultants conducted an eight-hour training with the interviewers on the study purpose, interview guide, and qualitative research methods. The training included role-playing and emphasized interpersonal interactions with participants, with a focus on issues relevant to this specific population, such as postpartum mental health, physical health, and infant care.

## Theoretical Approaches

As the study design and methods were developed, the researchers drew on theoretical approaches including the following:

- **Symbolic interactionism:** A theoretical perspective that suggests people's behavior is structured by the meanings they develop toward specific acts. These meanings are derived from social interaction and interpretation.
- **Grounded theory:** A methodology where researchers develop theories about social phenomena from analysis of empirical data.
- **Social psychological theories of the self:** Drawing on the disciplines of psychology and sociology, these theories focus on the ways in which self-reflexivity allows an individual to subjectively incorporate information provided via interactions with external others to shape their sense of self, which helps individuals to give meaning to experiences, especially to key life events.
- **Interactionist feminist theories of gender and sexuality:** Gender (whether experienced as an ascribed or achieved status) is a context-specific and salient factor in how an individual negotiates their sense of self and social identities during interactions with others, with cultural norms and values and with organizational policies and practices. In this way, most sexual values, norms, and identities are shaped by or reflect social constructions of gender.



## INTERVIEW GUIDE

Thank you for talking with me today about your experiences during pregnancy and childbirth. Is today still a good time for us to talk for about an hour or two?

### **Informed Consent Script**

To get us started, let's review the *Informed Consent* for this project. Did you get a chance to read the form? [If “yes”, skip to next paragraph. If “no”, say “I can read it aloud and answer any questions you have.”]

For this project, I would like to record my conversation with you so that I can correctly have your responses in your own words. Our conversation and this recording will be kept completely confidential. That means that your name will not be attached to this audio recording or to the notes I will take during our interview. Only members of the research team will have access to these recordings and notes that will be kept in a locked cabinet or saved on a secure computer network at our office. Your participation is completely voluntary. You may refuse to answer certain questions or you may choose to stop participating at any time without penalty or loss of compensation.

Do you have any questions for me about this project?

*If there are no additional questions, please complete and sign two copies of the Informed Consent Form (one will be provided to the participant and one will be maintained at DOHMH)*

### **I. Demographics:**

We're starting off by asking every person we talk with about their background.

- How old are you today?
- How do you identify in terms of race or ethnicity?
- What language do you speak at home?
- What type of health insurance, if any, do you have? (*Probe: Is it the same as before and during your pregnancy?*)
- What is your current job?
- Has your living situation changed since you had your baby?

- Who lives in your home with you? (*Probe: others who stay in your home but don't live there*)
- In times when you needed support during your pregnancy or afterward, which friends and family were most helpful to you? (*Probe: what specific tasks/help have they provided; ask until all members of the support network are identified*).

## II. General Pre-pregnancy Health:

- How would you describe your overall health before this recent pregnancy? (*Probes*)
  - How were you feeling physically? Any medical conditions?
  - How were you feeling emotionally?
  - Were you seeing anyone for regular check-ups or for specific medical issues? Tell me more about your healthcare visits prior to this pregnancy.
  - Before this pregnancy, were there any health care experiences like emergency room visits, annual exams with a gynecologist, surgeries that were especially memorable to you?

## III. Reproductive History:

Before we talk about your most recent birth, let's talk a little about what you knew about pregnancy and childbirth before you first became pregnant...

- What were your most important sources of information on pregnancy and childbirth?
- Probes: formal education or classes?
  - Books or online resources?
  - Advice from family or friends?

Now, just a couple of questions about your pregnancy and birth history:

- How many times have you been pregnant before? [*If one or more, then...*] In what year(s) did those pregnancies take place? What was the outcome of that/ [each] pregnancy? (*Probe up to most recent pregnancy*).

## IV. Pregnancy Health and Prenatal Care

Now I would like to hear about your most recent pregnancy...

- During your pregnancy, how were you feeling in your body / your physical health?
- During your pregnancy, how were you feeling emotionally?
- Did you have any concerns or worries during your pregnancy? (*Probe: pregnancy-related worries; other life or social stressors (e.g. housing, finances, etc.)*)

- Did you see a medical provider – doctor, midwife or nurse – anytime during this pregnancy?  
[If no probe reasons for not receiving prenatal care; skip to labor birth and postpartum probes]
  - Where did you go for these prenatal visits? How did you choose your prenatal care provider? (Probes: referral (who), past experience, did not feel had choice)
- Were there any traditional ways of supporting pregnancy that you wanted to follow?
- [If yes,] How did your health care providers respond to these traditions?
- Were there any alternative ways of supporting pregnancy that you wanted to follow?
- [If yes,] How did your health care providers respond?
- Can you tell me a bit more about your medical visits during pregnancy?
  - How did you feel you were treated there? (Probes: did you see the same provider each time? Same staff?)
  - [If Spanish-speaking] How did you feel speaking Spanish with your provider?
  - What did you like best about those visits?
  - What would have made those visits better for you?
  - How did you feel asking questions or raising concerns? Were you satisfied with their response? Ask for any examples.
  - Did your provider refer you to any specialists or make any other types of referrals? Tell me more about that.
  - Did you ever have difficulty getting to your prenatal care appointments or to any of your referral appointments? Tell me about that. (Probe: wait times for appointments)
  - Did you work or have a job during your pregnancy? [If not working outside home, skip to next question]
    - a. Did your job allow you to take sick leave for prenatal appointments?

## V. Childbirth experience

Now I would like to hear about your most recent childbirth experience. You can start wherever you would like to begin.

*Note: Throughout the story, ask about interactions with or referrals by healthcare practitioners – ask for examples, follow up with probes, such as ‘what happened next?’ until you have a full story or example of several interactions, particularly about the chain of events leading up to the birth or postpartum complication. Ask about the quality of the interaction, with such questions as: How did you feel when X was happening? Were you (or your support person) comfortable asking questions?; Did you feel the health care providers were explaining what was happening?*

**(Probes for labor, birth and postpartum, if not already mentioned in narrative so far)**

- What led you to give birth at hospital X? (*Probes: referral (who), past experience*)
- Who, if anyone, was with you during labor, the birth or after the birth?
  - Probe for who was there and for how long (partner/family/friends). Was anyone there the whole time you were in the hospital? Did others come and go?
- How did labor go for you? (*Probes: ask about length of labor, decision to go to hospital, how did you feel when X was happening? Did you feel the providers were explaining what was happening?*)
- Were you or your support team (*only if she mentioned others were with her*) comfortable asking questions? Why or why not?
- - Were there any traditional ways of supporting labor or giving birth that you wanted to follow when you were in labor or in the hospital?
    - [If yes,] How did hospital staff respond to these traditions?
  - Were there any alternative ways of supporting labor or giving birth that you wanted to follow when you were in labor or in the hospital?
    - [If yes,] How did medical providers respond?
- Tell me about the hours / days after giving birth while you were still in the hospital? How was it for you? (*Probes: if relevant, ask about blood transfusions, ICU admission, post-birth surgical intervention – if yes to any of these, then gently ask if they remember what led to them needing a [transfusion, ICU admission, surgical intervention]; Probe if offered birth control and how that felt*)
- We are interested to know about your interactions with different medical staff during and after the childbirth? (*Probes: concerns; responses; next actions; feelings; ...*)
  - Who spoke with you about your health condition (*Probes: was this a doctor, a nurse, other role in hospital? Also, clarify whether this occurred labor/birth/postpartum – could be more than one period*)?
  - What words were used to describe your health condition(s)?
  - What questions or concerns did you have during this time?
  - Were your questions or concerns addressed by anyone while you were in the hospital? [*If yes*] Ask for examples with details about who and when. [*If no*] Ask: What do you think are some reasons why your questions or concerns were not addressed?
- [*If not yet mentioned*] Were there any times during your birth or afterwards when you felt you were treated unfairly or without respect? Ask for any examples

- *[If not yet mentioned]* How did your childbirth experiences affect the way you or your family shared the news about your baby? [Probes: birth announcements, possibly via social media, sharing of photos/video, timing of sharing the news, etc.]

*[When they seem to have concluded talking about most recent childbirth experience...]*

- In what ways has this childbirth experience affected you? *(Probe for the following)*
  - Physical impact? Any other physical issues that arose during childbirth that affect your quality of life?
  - Emotional impact?
  - Financial impact?
  - Impact on relationships with family or friends?
  
- What have you been most concerned about since coming home from the hospital? *(Probe for the following)*
  - Feeding your newborn?
    - a. If wanted to breastfeed, any impact on breastfeeding?
  - Finances and work?
  - Insurance coverage?
  - Pain, disfigurement or damage to your body?
  - Future fertility?
  - Taking care of your family?
  
- What has helped you the most in terms of recovering from your experience? Tell me more about that. *(Probe for the following)*
  - Family?
  - Friends?
  - Partner/spouse/father-of-baby
  - Church?
  - Social agencies?
  
- Has anyone disappointed you or let you down while you've been recovering? *[If yes]* In what ways? *(Probe for the following)*
  - Health care providers?
  - Partner/spouse/father-of-baby?
  - Other friends or family members?
  
- Were you employed when you gave birth?
  - Did your job allow you to take maternity leave?
    - a. *[If yes]* For how long? *[Then]* How long did you take maternity leave?

- i. *[If less than allowed time]* What motivated you to return to work before the end of your possible maternity leave?
- b. *[If not clear whether returned to work]* Have you returned to your job yet?
  - i. *[If yes]* When did you go back?
    - l. *[If yes]* Has your work role or any of your work duties changed since you've returned to work?
  - ii. *[If no]* Are you planning to return to work?
    - l. *[If yes]* When do you plan to go back?]
- c. *[If not clear from previous answers]* Have your work plans changed because of your birth experience?

## VI. Postpartum Medical and/or Mental Health Treatment and Recovery

- Tell me about what happened after you went home from the hospital.
  - How have you been feeling physically in these past weeks?
  - How have you been feeling emotionally?
- In your family, are there traditions to be followed for a mother who's just given birth?
- *[If yes,]* Given your childbirth experiences, were you able to follow those traditions? (How or Why not?)
- Did you have an appointment for your own follow up care? When/did you go/what was that like? *(Probe if not able to make it to own follow up care appointments, then ask: how did your appointments go for your baby?)*
- What kinds, if any, of medical visits have you had since you came home from the hospital? *[If not clear, then ask if prescribed any medications, physical therapy, counseling, other?]*
  - *[If yes]* Did you go to the same clinic or hospital? Did you see a doctor or nurse that you'd seen before?

## VII. Concerns and Reflections

- What parts of your birth experience turned out the way you wanted?
- What do you think could have happened differently to make your birth (or postpartum) experience better?
- Are there things about your birth (or postpartum) experience that you still want to know or understand?

- What have you learned from this whole experience? (*Probes: What have you learned about doctors, nurses and hospitals from this experience? What have you learned about yourself from this experience?*)

### **VIII. Advice, in Retrospect**

- What advice do you have for providers that would help them give the best possible care to pregnant women? (*Probe: If you could make one change at the hospital where you gave birth (or received postpartum care), what would it be?*)
- [*If the interview is being conducted in Spanish...*] What pregnancy or childbirth advice would you have for those who are Spanish speaking?
- What advice would you give to women in your community who had a childbirth experience like yours? (*Probes: Advice while they're pregnant? Advice while in labor? Advice for recovery?*)
- What advice do you have for the family and friends of women in your community who have an experience like yours? [*If not clear: spouses, partners, family members*]
- When your baby is older, if they ask about what it was like for you to give birth, what might you tell them?
  - Would this be different if you had a (son/daughter)? [*whichever is different sex than baby*]
- As we conclude our interview today, what advice do you have for me about how I can improve the interview experience?

Thank you for taking the time to speak with me today. Remember that all the information you shared with me will be treated as confidential: your real name will never be linked with this project in any way. Please accept this gift card and MetroCard as a token of our appreciation for your participation in this project. We would also like to give you this folder with resources guides for new mothers. Thank you.

Permission to Contact Form (Hospital Recruitment)

## **New York City Maternal Health and Well-Being Study**



The **New York City Department of Health and Mental Hygiene** would like to speak with women who recently gave birth in local hospitals.

We want to learn from **YOU** how to improve the pregnancy, birth and recovery experience.

All participants will receive a **round-trip MetroCard** and **\$50 Visa card** for their time. The interview will take about 1-2 hours.

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**This study is not affiliated with this hospital.**

It is an independent project of the New York City Department of Health and Mental Hygiene. If you decide not to be contacted, there will be no change in your healthcare or benefits at this hospital.

**Our conversation will be kept completely confidential.**

Please complete the form if we can call you to schedule a time to talk. We won't contact you for a couple of months. We know it's a busy time.

You may return the form to me \_\_\_\_\_, or to your nurse. Feel free to call the number below to learn more about this study.

**Questions?**

# New York City Maternal Health and Well-Being Study Contact Form

Name: \_\_\_\_\_

Today's Date: \_\_\_\_\_

Hospital Discharge Date (expected): \_\_\_\_\_

## Main Phone Contact:

What phone number can we use to call you? \_\_\_\_\_

When is the best time to call this number? \_\_\_\_\_

Is it OK to text you at this number? [Yes or No]: \_\_\_\_\_

Is it OK to leave a voicemail at this number? [Yes or No]: \_\_\_\_\_

## Second Phone Contact:

Do you have another number where we can reach you? \_\_\_\_\_

When is the best time to call this number? \_\_\_\_\_

Is it OK to text you at this number? [Yes or No]: \_\_\_\_\_

Is it OK to leave a voicemail at this number? [Yes or No]: \_\_\_\_\_

# Scheduling Call Script

**Script for Follow-Up/Scheduling Phone Call** [To occur 10–12 weeks after hospital discharge]

Hi, may I speak with [*woman's full name*]?

Hi, my name is [*full name*] from the NYC Department of Health and Mental Hygiene. Thank you for your interest in participating in our study so that we can learn more about women's pregnancy and childbirth experiences. One of my colleagues spoke with you before you left the hospital and told you a little bit about our project. It's the one that offers participants a round-trip MetroCard and a \$50 Visa gift card for telling us your story.

Before we can schedule a time to talk, I have a few questions, to see if you are still eligible:

1. What was the name of the hospital where you gave birth (or postpartum)?
2. Did you have a vaginal or a C-section birth?
3. How are you feeling today?
4. How is your baby's health today?

[*If the woman is sick or the child is dead or severely sick*] I'm sorry to hear about [*your illness/loss/child is sick*]. If you'd like to talk with a counselor, then I can give you a name and number [*wait for response...provide appropriate resource*]. Unfortunately, based on your responses to my questions just now, we won't be able to include you in our study.

[*If the woman and child are in good health*] Great, I'm so glad you [*or your baby*] are doing well. So, today I'm calling to see if you're still interested in setting up a time to talk about your pregnancy and childbirth experience?

[*If yes*] It'd be great if we can find one to two hours when myself [*if interviewer*] or someone from my research team can interview you in-person in the next couple of weeks. Do you have any time open the week of [*date starting week that would be three months after hospital discharge date*]?

The discussion will be private and confidential. We'd like to meet you in person, say at your home or a [*insert other location, e.g. local community center or library*]*—*which place would work best for you? Of course, it's fine for you to have your baby with you during the interview.

Also, I want to make sure you know that we will protect your privacy throughout the study to the greatest extent possible. Your participation will be totally confidential, and we will not reveal your name or the names of the other mothers we're interviewing for this project.

If this all sounds good, then there's a short form I can go over with you by phone now and send you a copy by email, text, or regular mail. Which way works best for you [*ask for email or mailing address if that is preference*]? Then, on the day of your interview, you'll be asked to confirm that you understand what it means for you to participate in this project, and we'll answer any questions you have about the form or the study.

## Scripts for Repeat Contacts by Voicemail and Text Message

### Script for Voicemail Message:

Hi, my name is *[full name]* from the NYC Department of Health and Mental Hygiene. I'm calling to see if you're still interested in sharing your childbirth experiences for the NYC Maternal Health and Well-Being Study?

My colleague told you a bit about this study before you left the hospital a couple months ago. It's the one where participants receive a round-trip MetroCard and a \$50 Visa gift card.

If you are still interested, then please call me back at *[phone number]*. If I miss your call, then please leave me a message with your name, phone number, and the best times to reach you.

Thank you.

### Script for Text Message:

1. Hi, my name is *[full name]* from the NYC Dept. of Health & Mental Hygiene. You were told about our Maternal Health study in the hospital, after you gave birth at ... Are you still interested in talking about your childbirth experiences for this study? All participants will receive a round-trip MetroCard & \$50 Visa gift card

If interested, please call me at *[phone number]* to learn more...Thank you

## Community Recruitment Flyer (English Version)



## New York City Maternal Health and Well-Being Study

Call 646-799-7987



The **New York City Department of Health and Mental Hygiene** would like to speak with people who have experienced complications during childbirth.

If you gave birth within the past two years, we would like to learn from **YOU** about how to improve the pregnancy, birth and postpartum experience.

**Our conversation with you will be completely confidential and anonymous.**

If you are selected to participate, you will receive a **round-trip MetroCard** and **\$50 Visa card** for your time. The interview will take about one to two hours.

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This is an independent project of the Health Department and the Fund for Public Health in New York City. To learn more about this study, call the number on the tear-off strips below.

For more information, call 646-799-7987.

## Recruitment Flyer (Spanish Version)



## New York City Maternal Health and Well-Being Study (Estudio de salud y bienestar maternos de la Ciudad de Nueva York)

Llame al 646-799-7987



El Departamento de Salud y Salud Mental de la Ciudad de Nueva York desea conversar con personas que han experimentado complicaciones durante el parto.

Si dio a luz en los últimos dos años,  
nos gustaría aprender de **USTED**  
sobre cómo mejorar las experiencias del embarazo, el parto y el posparto.

**Nuestra conversación será estrictamente confidencial y anónima.**

Si es seleccionada para participar, recibirá una **tarjeta MetroCard de ida y vuelta** y una **tarjeta de regalo Visa de \$50** por su tiempo. La entrevista durará entre una y dos horas aproximadamente.

Este es un proyecto independiente del Departamento de Salud y del Fondo para la Salud Pública de la Ciudad de Nueva York. Para obtener más información sobre este estudio, llame al número que aparece a continuación en las tiras desprendibles.

Para obtener más información, llame al 646-799-7987.
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Spanish

# Community Participant Screener

# Maternal Health and Well-Being Study

## Community Recruitment Follow-Up Screening Form

Caller Name \_\_\_\_\_

Phone number \_\_\_\_\_ Best time to call \_\_\_\_\_

How did you hear about the study? \_\_\_\_\_

Baby's current age (in months) \_\_\_\_\_ Mother's age at birth \_\_\_\_\_

Hospital of Birth \_\_\_\_\_ Zip code of residence \_\_\_\_\_

Type of birth a) Vaginal \_\_\_\_\_ b) Caesarean \_\_\_\_\_

Baby's current health status a) well \_\_\_\_\_ b) sick \_\_\_\_\_ c) dead \_\_\_\_\_

Mother's current health status a) well \_\_\_\_\_ b) sick \_\_\_\_\_

<b>Reported complications during birth hospital admission</b>	<b>Yes/No</b>
Blood transfusions	
Intensive Care Unit admission before, during or after childbirth	
Severe hypertension or preeclampsia (high blood pressure)	
Seizures or loss of consciousness	
Heart failure or heart attack	
Blood clots in the leg or lung	
Unplanned hysterectomy (uterus removed by surgery)	

Other reported complications not listed above \_\_\_\_\_

\_\_\_\_\_

### *To be completed by DOHMH study staff member after call*

Caller eligibility status a) Eligible \_\_\_\_\_ b) Not eligible \_\_\_\_\_

Reason for eligibility/ineligibility \_\_\_\_\_

Date/Time of call \_\_\_\_\_ Screener initials \_\_\_\_\_

Call notes \_\_\_\_\_

\_\_\_\_\_

## Community Recruitment Sites

### **Community recruitment location types**

- Doula organizations
- Home visiting programs
- Community-based organizations (e.g., Catholic charities)
- Neighborhood-based clinics and health centers
- New York City Housing Authority notice boards
- YMCAs
- Shelter intake offices
- Neighborhood libraries
- Barbers and salons
- Laundromats
- Churches
- Community boards
- Early childhood programs (e.g., Healthy Start)
- Public assistance program offices (e.g., WIC)

### **Priority recruitment neighborhoods, by community district (CD)**

- Bronx: CD 6, 10
- Brooklyn: CD 5, 9, 16, 17, 18
- Queens: CD 5, 12, 13

## Informed Consent Form (Hospital Recruitment)



NEW YORK CITY DEPARTMENT OF  
HEALTH AND MENTAL HYGIENE  
Oxiris Barbot, MD  
*Commissioner*

New York City Department of Health and Mental Hygiene  
**Maternal Health and Well-Being Study**  
Principal Investigator: [insert name here]  
IRB Protocol #: 18-100

**Informed Consent for Hospital-Recruited Participants**

You are being asked to participate in a research study conducted by the New York City Department of Health and Mental Hygiene (DOHMH). This form tells you about the study and what you will be asked to do if you choose to participate. Please take the time to read this form. You may ask me any questions you have about the study. Your participation in this research study is voluntary.

**Purpose**

We are doing this research study to learn about women's experiences during pregnancy, childbirth and after they leave the hospital. You are being asked to participate because you had a blood transfusion or were admitted to the Intensive Care Unit (ICU) when you gave birth, or in the days after giving birth.

**Study Procedures**

If you agree to take part in this study, you will be asked to share your pregnancy and childbirth story with a trained researcher. The researcher is not connected to the hospital where you gave birth. It will be a one-time face-to-face discussion that will last 1-2 hours. It will take place at a private and quiet location that works best for you. This could be your home, library or community center, for example. We will audio record the discussion so that we have your full story in your own words.

We also want to obtain the hospital records from where you gave birth or were treated after the birth. This is to better understand the medical background to your story. If you choose to share these records with us, you will be asked to sign a separate HIPAA form.

**Risks and Benefits**

As you share your pregnancy and childbirth story, you may have emotional discomfort or strong feelings. The interviewer is trained to be sensitive and can give you some resources if you find the discussion upsetting.

We plan to safeguard your information to the greatest extent possible but another possible risk is the loss of confidentiality (privacy). The safeguards are mentioned in the confidentiality and privacy section.



NEW YORK CITY DEPARTMENT OF  
HEALTH AND MENTAL HYGIENE  
Oxiris Barbot, MD  
*Commissioner*

You may not receive any direct benefits for being in this study, but the information you share could help us improve the care given to other pregnant women and new mothers.

### **Compensation**

You will receive a round-trip MetroCard and \$50 visa gift card for your time.

### **Confidentiality and Privacy**

We will make every effort to keep your personal information confidential to the extent of the law. To help protect your confidentiality and privacy, we will not link your name to any information you share with us. We will write down the information from the audio recording but will remove all identifying information from your story. The company we hire to help us create this document will also agree to safeguard your privacy (confidentiality).

All research materials will be kept in a locked file cabinet at the researcher's office. Any materials stored electronically will be kept on password protected computers. Only members of the research team will have access to these files. The files and recordings will be destroyed when the study is completed. If the information is published or presented at a meeting, your name and personal information will not be shared or used.

### **Participation**

Your participation in this interview is voluntary. If, after the interview begins, you decide you no longer want to participate, you can withdraw your consent and we will stop the interview. You may also refuse to answer any questions. If you decide not to participate or to not answer certain questions, there will be no penalty or loss of compensation.

### **Questions**

If you have any questions about the study, you may contact [insert name and contact here]

If you have questions or concerns about your rights or welfare as a research participant, you may contact the New York City Department of Health and Mental Hygiene Institutional Review Board (IRB) at 347-396-6118 or email at [irbadmin@health.nyc.gov](mailto:irbadmin@health.nyc.gov).



NEW YORK CITY DEPARTMENT OF  
HEALTH AND MENTAL HYGIENE  
Oxiris Barbot, MD  
*Commissioner*

**Consent**

Please check the box and initial below if you are in agreement with the following statements:

- \_\_\_\_\_ Initial      I agree to be contacted by DOHMH with any follow-up questions.
  
- \_\_\_\_\_ Initial      I agree to sign a separate HIPAA form so that we can access your childbirth or postpartum hospital records for confidential research purposes.

I have read this consent form and the research study was explained to me. I voluntarily agree to be in this study. A copy of this consent form will be provided to me after I sign it. By signing this consent form, I have not given up any of the legal rights that I would have if I were not a participant in the research study.

\_\_\_\_\_  
Name of Participant (please print)      Participant Signature      Date

\_\_\_\_\_  
Name of Person Obtaining Consent      Person Obtaining Consent Signature      Date

## Informed Consent Form (Community Recruitment)



NEW YORK CITY DEPARTMENT OF  
HEALTH AND MENTAL HYGIENE  
Oxiris Barbot, MD  
*Commissioner*

New York City Department of Health and Mental Hygiene  
**Maternal Health and Well-Being Study**  
Principal Investigator: [insert name here]  
IRB Protocol #: 18-100

**Informed Consent for Community-Recruited Participants**

You are being asked to participate in a research study conducted by the New York City Department of Health and Mental Hygiene (DOHMH). This form tells you about the study and what you will be asked to do if you choose to participate. Please take the time to read this form. You may ask me any questions you have about the study. Your participation in this research study is voluntary.

**Purpose**

We are doing this research study to learn about women's experiences during pregnancy, childbirth and after they leave the hospital. You are being asked to participate because you had a blood transfusion or were admitted to the Intensive Care Unit (ICU) when you gave birth, or in the days after giving birth.

**Study Procedures**

If you agree to take part in this study, you will be asked to share your pregnancy and childbirth story with a trained researcher. It will be a one-time face-to-face discussion that will last 1-2 hours. It will take place at a private and quiet location that works best for you. This could be your home, library or community center, for example. We will audio record the discussion so that we have your full story in your own words.

**Risks and Benefits**

As you share your pregnancy and childbirth story, you may have emotional discomfort or strong feelings. The interviewer is trained to be sensitive and can give you some resources if you find the discussion upsetting.

We plan to safeguard your information to the greatest extent possible but another possible risk is the loss of confidentiality (privacy). The safeguards are mentioned in the confidentiality and privacy section.

You may not receive any direct benefits for being in this study, but the information you share could help us improve the care given to other pregnant women and new mothers.



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*Commissioner*

### **Compensation**

You will receive a round-trip MetroCard and \$50 visa gift card for your time.

### **Confidentiality and Privacy**

We will make every effort to keep your personal information confidential to the extent of the law. To help protect your confidentiality and privacy, we will not link your name to any information you share with us. We will write down the information from the audio recording and we will remove all identifying information from your story. The company we hire to help us create this document will also agree to safeguard your privacy (confidentiality).

All research materials will be kept in a locked file cabinet at the researcher's office. Any materials stored electronically will be kept on password protected computers. Only members of the research team will have access to these files. The files and recordings will be destroyed when the study is completed. If the information is published or presented at a meeting, your name and personal information will not be shared or used.

### **Participation**

Your participation in this interview is voluntary. If, after the interview begins, you decide you no longer want to participate, you can withdraw your consent and we will stop the interview. You may also refuse to answer any questions. If you decide not to participate or to not answer certain questions, there will be no penalty or loss of compensation.

### **Questions**

If you have any questions about the study, you may contact the Principal Investigator,  
[insert name and contact here]

If you have questions or concerns about your rights or welfare as a research participant, you may contact the New York City Department of Health and Mental Hygiene Institutional Review Board (IRB) at 347-396-6118 or email at [irbadmin@health.nyc.gov](mailto:irbadmin@health.nyc.gov).



NEW YORK CITY DEPARTMENT OF  
HEALTH AND MENTAL HYGIENE  
Oxiris Barbot, MD  
*Commissioner*

**Consent**

Please check the box and initial below if you are in agreement with the following statements:

- \_\_\_\_\_ Initial      I agree to be contacted by DOHMH with any follow-up questions.
  
- \_\_\_\_\_ Initial      I agree to sign a separate HIPAA form so that we can access your childbirth or postpartum hospital records for confidential research purposes.

I have read this consent form and the research study was explained to me. I voluntarily agree to be in this study. A copy of this consent form will be provided to me after I sign it. By signing this consent form, I have not given up any of the legal rights that I would have if I were not a participant in the research study.

\_\_\_\_\_  
Name of Participant (please print)      Participant Signature      Date

\_\_\_\_\_  
Name of Person Obtaining Consent      Person Obtaining Consent Signature      Date

# Distress Protocol Sample

## Severe Maternal Morbidity Project Distress Protocol

This version was adapted for broad use within DOHMH for research involving participants who may be in distress. It is largely based on the WTCHR protocol.

It is possible that some respondents will experience some form of psychological distress during an interview due to remembering the events that we are asking them about. The psychological distress may include normal reactions such as anger, frustration/impatience, and sadness. This protocol is a guideline to help interviewers (SMM Project staff interviewing respondents) identify potentially distressed respondents, to provide the assistance respondents may need, and to standardize the SMM Project team's response to these situations.

### A. Handling Respondents in Distress

This is a “respondent-driven” protocol for dealing with possible distress and crisis situations. This means that we react to respondents' signs and needs by offering them choices. Key to this protocol is seamless communication between the interviewer, the supervisor, and the manager, especially in Level 2 and 3 situations.

#### **Step 1: Recognize that a respondent is possibly distressed.**

The following are signs that may indicate a respondent is experiencing distress:

- Hesitancy to answer a question or questions;
- Refusal to answer questions or to continue the interviewing process;
- Lowering of the volume or tone of voice;
- Responding in an agitated manner by raising his/her voice or using inappropriate language;
- Crying;
- Indications of tremors, a quivering in the respondent's voice;
- Disorganization, dissociation, or non-responsiveness to questions asked

**Step 2: Observe the level of distress that a respondent is apparently experiencing.** Below is a table that provides some guidance as to what indicators you might come across that a person may be in distress or approaching a crisis.

LEVEL OF DISTRESS	SIGNS OR INDICATORS OF POSSIBLE DISTRESS
LEVEL 1	<ul style="list-style-type: none"> <li>• Change in voice tone or volume.</li> <li>• Changes in focus.</li> <li>• Hesitancy to answer questions.</li> <li>• Provides non-relevant answers to questions asked.</li> <li>• Displays an unwillingness or hesitancy to continue</li> </ul>
LEVEL 2	<p>Level 1 signs PLUS any of:</p> <ul style="list-style-type: none"> <li>• Displays signs of distress that may include long pauses, or sighing</li> <li>• Sobbing, weeping, and/or crying.</li> <li>• Displays other obvious signs of agitation.</li> <li>• Displays flat voice tones.</li> <li>• Being non-responsive.</li> <li>• Provides nonsensical/bizarre answers.</li> </ul>
LEVEL 3 <u>*SEEK IMMEDIATE HELP</u>	<ul style="list-style-type: none"> <li>• If a respondent poses an immediately risk to themselves or others (i.e. suicidal or homicidal ideation or intent); the respondent talks about passive or active thoughts to harm themselves or others with or without a plan</li> <li>• Respondent asks for immediate help from emergency services or 911</li> </ul>

**Step 3: Respond appropriately to the situation.**

Based on your observation of the level of distress it is imperative that you react appropriately, with sensitivity and empathy. Active listening skills are key to determining whether the level of distress the respondent is experiencing.

***NOTE:** All calls must be made from a phone that has the ability to make a 3-way call; please verify that your phone has this feature before attempting to make any calls*

<b>Level 1: Next Steps</b>	
<b>Interviewer Actions</b>	<p>The primary response to a level 1 event is <b>pausing the interview</b> to acknowledge the respondent’s distress and offer a break. A good start is to also summarize what the respondent is stating (e.g., <i>Let me stop and summarize what we’ve just talked about. You said [...] Did I miss anything?</i>).</p> <p>Offer the respondent a short break. Employ empathy and remind the respondent that they are in control of when the interview ends, or when they need a break. For example:</p> <p><i>“I know that this topic can be stressful. Would you like to continue? Can I get you some water?”</i> OR <i>“I know that this is a long interview and may be stressful. Would you like to take a break?”</i></p> <p><b><u>Does the respondent want to continue with the interview?</u></b></p> <p><b>“YES”</b>: Continue with sensitivity.</p> <p><b>“YES, BUT NOT NOW”</b>: Suspend and speak to supervisor about next steps.</p> <p><b>“NO, DON’T WANT TO CONTINUE EVER”</b>: Terminate the interview.</p> <p>Level 1 signs and indicators of distress are normal. Depending on the situation, you may want to offer to provide the respondent information about NYC WELL. If you decide to provide NYC WELL information, you should first ask if the respondent is interested in receiving resources. You can say, “Have you heard of NYC WELL? They are a crisis hotline and information and referral service.” <b><u>You should feel free to impart this information, but take care not to do so prematurely or unnecessarily. We do not want to offend anyone by assuming they are upset or traumatized when in fact they do not want to give information for some other reason.</u></b></p> <p>After the interview, contact the supervisor to debrief them on the situation, outcome, and whether NYC WELL was contacted.</p>
<b>Supervisor Actions</b>	Supervisor will debrief the situation with the interviewer. Supervisor will then inform the manager of the outcome.
<b>Management Actions</b>	Manager reviews the case and might follow up with the supervisor and interviewer for more information.

<b>Level 2: Next Steps</b>	
<b>Interviewer Actions</b>	<p>The primary response to a level 2 event is <b>pausing the interview and gently suggesting to call NYC WELL together</b>. Affirm what you hear the respondent stating to be sure you have an accurate understanding of how they are feeling.</p> <p><i>Example: “I have a sense this may be difficult for you to talk about right now. Let me stop and summarize – I want to be sure I understand as best I can. You said [...] Did I miss anything?”</i></p>

	<p><b><u>Does the respondent want to be connected to NYC WELL?</u></b></p> <p><b>“YES”:</b> Offer to stay with the respondent on the call with NYC WELL as a support:</p> <p>Example: <i>“I’ll stay with you until we can get someone from NYC WELL on the line. If you would like me to be with you during that call, I will stay for that, too. They will speak to you generally about how you are feeling and will explain what resources they can provide to you.”</i></p> <p>Before calling NYC Well, ask the respondent if they would be comfortable providing their phone number to NYC WELL. Remind them that their phone number will be used for follow up, but otherwise the call will be confidential. Use respondent’s phone to call NYC WELL, in case the respondent indicates that they would like you to leave before the call is over.</p> <p><b>“NO”:</b> Honor the respondent’s wishes. Write down the information for NYC WELL and offer encouragement to reach out. Offer the respondent a short break.</p> <p>When there is a break, discretely text the supervisor that a Level 2 situation has occurred.</p> <p><b><u>Does the respondent want to continue with the interview?</u></b></p> <p><b>“YES”:</b> Continue with sensitivity.</p> <p><b>“YES, BUT NOT NOW”:</b> Suspend and speak to supervisor about next steps.</p> <p><b>“NO, DON’T WANT TO CONTINUE EVER”:</b> Terminate the interview and thank them.</p> <p>Once the interview is over, call your supervisor and debrief them on the events. If you need immediate guidance, briefly excuse yourself from the interview and call your supervisor.</p> <p><b>NOTE: Once NYC WELL is on line with the respondent, NYC WELL is responsible for assessing the respondent’s level of distress and calling local emergency services if needed.</b></p> <p><b>NOTE: If the situation escalates to Level 3 of the Distress Protocol while NYC WELL is being called, follow the Level 3 protocol from this point on.</b> If you are not certain whether or not the case has escalated to a Distress Level 3, connect the respondent with NYC WELL immediately and let NYC WELL conduct an assessment of the respondent and situation.</p>
<b>Supervisor Actions</b>	Supervisor will confirm or change, if necessary, the level of distress based on information from the interviewer. Supervisor will inform the manager of the situation.
<b>Management Actions</b>	Manager reviews the case and might follow up with the supervisor and interviewer for more information.

**Level 3: Next Steps**

<b>Interviewer Actions</b>	<p>The primary response to a level 3 event is an immediate “warm handoff” by calling NYC WELL with the respondent or, less frequently, calling 911. The supervisor should be notified as soon as possible.</p> <p><b>IF THE RESPONDENT TALKS ABOUT “SUICIDE”, OR “WISHING ANOTHER PERSON WAS DEAD”, OR “LIFE IS NOT WORTH LIVING ANYMORE”, OR ASKS TO BE CONNECTED WITH THEIR MENTAL HEALTH PROVIDER, OR ANYTHING SIMILAR, you should:</b></p> <p>Affirm what you hear and offer to connect the respondent to NYC WELL: <i>“Let me stop and summarize what we’ve just talked about. You said [...]. Did I miss anything? There is a service set up to help people who are feeling upset or overwhelmed. This confidential service is called NYC WELL and is available 24 hours/day, 7 days/week. NYC WELL is a crisis hotline and information and referral service. They have experienced counselors who will listen and talk to you about how you are feeling. They can tell you about services available in your area that may help you.”</i></p> <p>Call NYC WELL with the respondent and introduce the worker to the respondent. You can say: <i>“NYC WELL, I have (Respondent’s name) with me. S/he would like to talk with you about how they are feeling.”</i> Hand the phone to the respondent. Stay with the respondent during the call.</p> <p><b>NOTE: Once NYC WELL is on line with the respondent, NYC WELL is responsible for assessing the respondent’s level of distress and calling local emergency services if needed.</b></p> <p><b>IF RESPONDENT POSES AN IMMEDIATE THREAT TO THEMSELVES OR SOMEONE ELSE OR ASKS TO BE CONNECTED TO 911 OR EMERGENCY SERVICES,</b> tell the respondent that you must contact your supervisor, a trained mental health professional. Call your supervisor immediately and once they are on the phone, affirm what you hear so that the supervisor understands:</p> <p><i>“Let me stop and summarize what we’ve just talked about. You said [...]. Did I miss anything? I am going to ask my supervisor to make a call to local emergency services to have someone come out and talk with you.”</i> Keep the person informed about what is happening. Following the supervisor’s guidance, collect information necessary to call emergency services or another party (depending on circumstances) who can provide immediate help.</p> <p><b>If the respondent refuses to be assisted by emergency services</b> still call the supervisor. Following the supervisor’s guidance, either call NYC WELL and connect the respondent to NYC WELL or stay with the respondent while your supervisor calls emergency services or another party. Do not leave until your supervisor instructs you to or the respondent asks you to.</p>
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	<p><b>If respondent asks you to leave before emergency services arrives</b> employ empathy and try to resume conversation with the respondent until emergency services arrive. If the respondent confirms that they would like you to leave, you should leave, inform your supervisor and contact NYC WELL. Explain the situation to NYC WELL in full detail (leaving out the respondent’s name) and request guidance for how the situation should be further handled. NYC WELL’s recommendations should be discussed with the supervisor and implemented to the best of the project’s abilities.</p>
<p><b>Supervisor Actions</b></p>	<p><b>IF RESPONDENT POSES AN IMMEDIATE THREAT TO THEMSELVES OR SOMEONE ELSE OR ASKS TO BE CONNECTED TO 911 OR EMERGENCY SERVICES AND THE SUPERVISOR DETERMINES THAT EMERGENCY SERVICES SHOULD BE CALLED, THEN THE SUPERVISOR:</b></p> <ul style="list-style-type: none"> <li>• Copies down the verified telephone number and home address of the respondent (if she does not have it already)</li> <li>• Immediately calls NYC emergency services.</li> <li>• Provides the verified address, name, and phone number of the respondent to emergency services.</li> <li>• Explains to Emergency Services the facts as you know them (e.g., the respondent has threatened to harm or kill himself/herself or someone else)</li> <li>• If safe and appropriate, the interviewer can stay with the respondent until emergency services have arrived or verified arrival by speaking with the respondent. Ask the interviewer if he/she needs to discuss their feelings with NYC WELL</li> <li>• If respondent asks the interviewer to leave before verification of the arrival of emergency services, the supervisor contacts emergency services periodically (every 30 minutes) until emergency services provide a response</li> <li>• If a level 3 situation is encountered it should immediately be reported to the manager.</li> </ul>
<p><b>Manager Actions</b></p>	<ul style="list-style-type: none"> <li>• Reviews and files the adverse event report with the IRB</li> <li>• Debriefs with the interviewer and supervisor as soon as possible</li> <li>• Notifies the IRB of the event within 24 hours</li> <li>• Additional actions may be taken which may include: <ul style="list-style-type: none"> <li>○ Sending a follow-up letter to the respondent (with resource information, if not given during the interview)</li> <li>○ Routinely reviewing all Level 3 cases with the interviewer, supervisor, and consultants</li> <li>○ Providing advice about the need to change or revise protocols as a result of the event, or the appropriate follow-up to the event</li> </ul> </li> <li>• These actions may be taken regardless of whether or not contact was made between the respondent and NYC WELL, emergency services, or another party</li> </ul>

# Resource Guide Sample

## Severe Maternal Morbidity Project NYC Resource Guide

The following list includes many, but not all, supportive resources in New York City. **For immediate mental health support, contact NYC WELL by calling 1-888-NYC-WELL (1-888-692-9355) or text “WELL” to 65173 or visit [nycwell.cityofnewyork.us](http://nycwell.cityofnewyork.us). Counselors are available all day every day.** If you are experiencing an emergency, call 911 now or go to your nearest emergency room.

### Manhattan

#### **The Institute for Family Health at 17<sup>th</sup> Street**

230 West 17<sup>th</sup> Street (between 7<sup>th</sup> and 8<sup>th</sup> Avenues), New York, NY 10011

Intake: 212-206-5200

Primary health care and supportive counseling available. Some providers specialize in treating trauma. Medicaid accepted. Spanish and English speaking providers available. No childcare offered, but you can bring your children to appointments. There is usually no waitlist.

#### **Family Health Center of Harlem**

1824 Madison Avenue, New York, NY 10035

Intake: 844-434-2778

Primary health care and supportive counseling available. Some providers specialize in treating trauma. Medicaid accepted. Spanish and English speaking providers available. No childcare offered, but you can bring your children to appointments. There is usually no waitlist.

#### **The Institute for Family Health Center for Counseling at the Alliance**

64 West 35<sup>th</sup> Street, 3<sup>rd</sup> Floor, New York, NY 10001

Intake: 646-741-9100

Primary health care and behavioral health services offered, with providers who specialize in treating postpartum depression. All services are trauma-informed. There is no childcare, but children can be brought into appointments. There is sometimes a waitlist, but you can be bumped up depending on the urgency. Medicaid accepted.

#### **New York-Presbyterian Hospital/Weill Cornell Medical Center Payne Whitney Women’s Program Counseling and Medication Management**

525 East 68<sup>th</sup> Street, New York, NY 10065

Intake: 212-746-4850

Emergency number: 212-517-1684

Related to pre-conception, pregnancy, postpartum, lactation, pregnancy loss, infertility, premenstrual dysphoric disorder, menopause, and other issues. Support Group available. Most insurance plans accepted, including Medicaid. If you call and leave a message, it can take up to 3 days to receive a call-back.

\*Comprehensive Psychiatric Emergency Program (CPEP). Emergency evaluations 24 hours a day, 7 days a week. Contact: 888-694-5700

**New York Presbyterian Hospital/Columbia University  
Women's Program in the Department of Psychiatry**

180 Fort Washington Avenue, New York, NY, 10032

Intake: 212-305-6001

Consultation and ongoing treatment with psychiatrists and psychologists who have experience in reproductive and perinatal psychiatry. They accept private pay, Aetna, United Healthcare, Oxford, Blue Cross Blue Shield. If you call and leave a message, it might take up to 2 days to receive a call back.

**New York Presbyterian Hospital/Columbia University**

Adult Outpatient Psychiatry Clinic

365 West 165<sup>th</sup> Street, 4<sup>th</sup> & 6<sup>th</sup> Floors, New York, NY 10011

Intake: 212-305-5977

Generalists and specialists who provide perinatal and postpartum mental health treatment. They accept most insurance plans, including Medicaid. There is usually a waitlist of 3-4 weeks. Children over 10 years old can be left in the waiting room alone.

**Lenox Hill Hospital (MEETH) Outpatient Center for Mental Health**

100 East 77th Street, New York, NY 10075

Intake: 212-702-7614

Alternate contact: Inga Blom, PhD 212-702-7376/iblom@northwell.edu

Clinical Services provided for perinatal mood and anxiety disorders include: Individual psychotherapy, Dyadic psychotherapy, psychopharmacological consultation and treatment and Postpartum Support Group. Most insurances accepted including Medicaid. Does not take United and Metroplus Medicaid. Babies are welcome at appointments.

**Bellevue Psychiatry Outpatient Clinic**

462 1<sup>st</sup> Avenue, New York, NY 10016

Intake: 212-562-2526

Generalists and specialists who provide perinatal and postpartum mental health treatment. Individual and group therapy available. If you cannot reach someone, leave a message and they will call you back. They accept most insurance plans, including Medicaid. English and Spanish speaking providers available.

**Laura Venuto, MA, MSAEd, PsyD**

114 E 90th Street, Suite 1A, New York, NY 10128

Intake: 540-583-6886

Licensed Psychologist specializing in helping children, adolescents, and adults cope with depression, anxiety, maternal mental health issues, trauma, abuse, and loss and women undergoing a major life transition such as motherhood and parenting. Provides psychological assessment and individual psychotherapy. Runs support group for new mothers at the 92nd Street Y. Accepts Sliding Scale.

### **Postgraduate Center for Mental Health**

71 West 23rd Street, New York, NY 10010

Intake: 212- 576-4104

Postgraduate Center for Mental Health is dedicated to serve the housing and the mental health needs of individuals and families. The Postgraduate Adult and Child Clinic provide affordable community based mental health treatment for adults, children from ages 5 and up, adolescents, and families. The Center for Adult Psychotherapy offers comprehensive mental health services for individuals with history of chronic mental illness. Services include individual and group therapy as well as medication management. Medicaid is accepted.

### **East Harlem Neighborhood Health Action Center**

158 E 115<sup>th</sup> Street, New York, NY 10029

Phone: 855.789.8760

The Neighborhood Health Action Center uses a holistic approach to primary care, activates spaces for community organization and planning, and connects residents to neighborhood-based social services. You can go to an Action Center for primary care, mental health care, dental care (in some cases), and referrals to a network of local services, health and wellness classes, workshops, and activities.

## **Brooklyn**

### **Brooklyn Center for Psychotherapy**

300 Flatbush Avenue, Brooklyn, NY 11217

Intake: 718-622-2000

Behavioral health services available for both adults and children. Medicaid accepted. Psychiatrists, psychologists, registered nurses, social workers, and mental health counselors work together to provide comprehensive services. Services available in Spanish and English. For a non-urgent situations there is usually a waitlist of 6-8 weeks. Childcare is available on-site after 5pm and on weekends.

### **Healthy Connections Clinic**

6025 Sixth Avenue, Brooklyn, NY 11220

Intake: 718-630-7991

Provides trauma-informed treatment to adults and children. Social workers, psychiatrists, and nurse practitioners work together to assess, diagnose, and treat trauma disorders. Medicaid is accepted. The waitlist is usually 4-6 weeks. There is no childcare on-site, but children can come into the appointments.

### **Park Ridge Family Health Center at NYU Langone**

6317 Fourth Avenue, Brooklyn, NY 11220

Intake: 718-630-7942

Other number: 718-907-8100

Full range of primary healthcare services for the entire family including nutrition counseling, HIV counseling, and behavioral healthcare services available. Medicaid and almost all other insurance accepted, as well as sliding scale. Providers do not specialize in treating postpartum depression, but

can connect you with doctors from more than 30 adult and pediatric medical and surgical specialties within the Family Health Center network. English and Spanish speaking providers available. No childcare but offer “baby-friendly” areas. Appointments are usually immediately available.

**Park Slope Family Health Center at NYU Langone**

220 13<sup>th</sup> Street, Brooklyn, NY 11215

Intake: 718-832-5980

Full range of primary healthcare services for the entire family; nutrition counseling, HIV counseling, and behavioral healthcare services available. Medicaid and almost all other insurance accepted, as well as sliding scale. Providers do not specialize in treating postpartum depression, but can connect you with doctors from more than 30 adult and pediatric medical and surgical specialties within the Family Health Center network. English and Spanish speaking providers available. No childcare but offer “baby-friendly” areas. Appointments are usually immediately available.

**New York Presbyterian Methodist**

**It Takes a Village: Postpartum Mood and Anxiety Support Group**

501 6<sup>th</sup> Street, Brooklyn, NY 11215

Intake: Helen Reingold, Psy.D., 718-780-3771 or Carol John, LMSW, 718-246-8525

Discuss the challenges of being a parent/caregiver in a safe, supportive environment. Second Wednesday of every month from 1pm - 2pm. Contact intake before attending.

**The Marvin Kaylie Tikvah Center at OHEL**

2925A Kings Highway, Brooklyn, NY 11229

Intake: 718-382-0045

General supportive counseling with a social worker available, and can refer elsewhere for more specialized needs. Medicaid and almost all other insurance accepted, as well as sliding scale. English, Spanish, Russian and Hebrew speaking providers available.

**Institute for Family Health**

**Cadman Family Health Center**

300 Cadman Plaza West, 17<sup>th</sup> Floor (inside One Pierrepont Plaza), Brooklyn, NY 11201

Intake: 718-822-1818

Offers primary health care and therapeutic supports. Accepts Medicaid.

**South Beach Psychiatric Center**

250 Baltic Street, Brooklyn, NY 11201

Intake: 718-855-3131

General supportive counseling offered. They accept most insurance plans, including Medicaid. The waitlist for services can be up to a few weeks. They will resume specialized counseling services in 2019.

### **Brownsville Neighborhood Health Action Center**

259 Bristol Street, Brooklyn, NY 11212

Phone: 718.312.6130

The Neighborhood Health Action Center uses a holistic approach to primary care, activates spaces for community organization and planning, and connects residents to neighborhood-based social services. You can go to an Action Center for primary care, mental health care, dental care (in some cases), and referrals to a network of local services, health and wellness classes, workshops, and activities.

## **Queens**

### **Creedmore Psychiatric Center – Steinway Wellness and Recovery Center**

38-11 Broadway, 3<sup>rd</sup> Floor, Astoria, NY 11103

Intake: 718-726-5953

Offers medication management and generalized counseling. Accepts Medicaid and most other forms of insurance. The waitlist for services can be up to a few weeks. English, Greek, and Russian speaking providers available.

### **Mental Health Providers of Western Queens, Woodside Clinic**

61-20 Woodside Avenue, Woodside, NY 11377

Intake: 718-672-1705

This is an outpatient mental health clinic for ages 5 and up that primary offers general counseling services. Waitlist can be up to a few weeks. English and Spanish speaking providers available.

## **Bronx**

### **Riverdale Mental Health Association/Mosaic Mental Health**

5676 Riverdale Avenue, Suite 202, Bronx, NY 10471

Intake: 718-796-5300/[rmha@rmha.org](mailto:rmha@rmha.org)

Provide treatment for the full range of behavioral and psychiatric problems includes group, family, couples, and individual therapy, as well as medication consultation. Children's play therapy and other services for children available, too. Medicaid and most other insurances accepted.

### **Walton Family Health center and Center for Counseling**

1894 Walton Avenue, Bronx, NY 10453

Primary Care Intake: 718-583-3060

Therapy Intake: 718-583-2508

Dental Care Intake: 718-583-2700

Primary health care and generalized counseling available. Medicaid and most other insurances accepted. English and Spanish speaking providers available. Appointments usually available within a week.

**Mt. Hope Family Practice**

130 West Tremont Avenue, Bronx, NY 10453

Intake: 718-583-9000

You must see a primary care doctor in order to receive therapeutic services here. Provide specialized postpartum depression and trauma treatment. English and Spanish speaking providers available.

**Stevenson Family Health Center**

731 White Plains Road, Bronx, NY 10473

Primary Care Intake: 718-589-8775

Counseling Intake: 718-822-9140

Dental Care Intake: 718-395-8350

Primary care, behavioral health, and dental care offered. Medicaid and most other insurances accepted. English and Spanish speaking providers available. Appointments usually available within a week.

**Bronx Child and Family Mental Health Center (New York Psychotherapy and Counseling Centers)**

579 Courtlandt Avenue, Bronx, NY 10451

Intake: 718-485-2100

Outpatient mental health clinic providing children 3+, adults, and families with individual and family therapy and referrals. Some services include: Individual Verbal Therapy, Play Therapy, Art Therapy and Crisis intervention. Specialized services for postpartum depression available. Accepts Medicaid. Providers are usually available same day or next day.

**Fordham-Tremont Women and Family Center**

2021 Grand Concourse, 6th Floor, Bronx, NY 10453

Main: 718-960-3311

Intake: 718-960-3071

Uses mental health center that provides trauma survivors with therapeutic counseling, case management, crisis intervention, and psychiatric care. Mental health programs include domestic abuse/victims' services, play therapy and counseling for children. Walk-ins are also welcome from 9am-3pm. Medicaid accepted.

**Bronx Lebanon Hospital Adult Outpatient Clinic**

1276 Fulton Avenue, 8<sup>th</sup> Floor, Bronx, NY 10456

Intake: 718-579-7395/718-759-7385

Providers therapy to people 18 years and older. Medicaid is accepted.

**The Vida Guidance Center**

4419 3<sup>rd</sup> Avenue, 1<sup>st</sup> Floor, Bronx, NY 10457

Intake: 718-364-7700

Provides individual, group, and family therapy to people 5 years and older. Services available in Spanish and English. Medicaid accepted.

**Puerto Rican Family Institute**

4123 3<sup>rd</sup> Avenue, Bronx, NY 10457

Intake: 718-299-3045

Mental health services for children and adults, including individual, group, and family therapy. Medicaid is accepted. Services available in Spanish.

**Group Attachment-Based Intervention (GABI)**

1225 Morris Park Avenue, Bronx, NY 10461

Van Etten, Building 5

Intake: 718-839-7200

Parent-child group for families with children ages 0-3. Families are welcome to attend group sessions in the morning or afternoon Monday, Thursday, & Friday. Medicaid is accepted. Services are available in Spanish.

**The Max and Celia Parnes Family Psychological and Psychoeducational Services Clinic**

The Louis E. and Dora Rouso Community Health Center

1165 Morris Avenue, Room C-14, Bronx, NY 10461

Intake: Marilyn Gotay, 718-430-3852

The Parnes Clinic provides low-cost, confidential, state-of-the-art mental health services for children, adolescents, adults, couples and families. Clients who are not accommodated by the Parnes Clinic are offered referrals to other agencies.

**Montefiore Behavioral Health Center**

2527 Glebe Avenue, Bronx, NY 10461

Intake: 718-904-4414, 718-904-4476, 718-904-4434

Offers comprehensive therapy and psychiatric services for adults and children. Walk-in appointments are available, but calling ahead is advised. Medicaid accepted.

**Montefiore (Wakefield) Outpatient Clinic**

4401 Bronx Boulevard, Bronx, 10470

Intake: 718-304-7000

**Montefiore (Moses) Outpatient Clinic**

111 East 210<sup>th</sup> Street, Bronx, NY 10467

Intake: 718-920-4295

Montefiore Behavioral Health Center provides comprehensive services for adults, children and adolescence. Treatment is conducted by highly skilled licensed clinical social workers, psychiatric nurse practitioners and board-certified psychiatrists. Scheduled and walk-in appointments are available at two locations. Medicaid accepted. Spanish and English speaking providers available.

**Postgraduate Center for Mental Health**

1775 Grand Concourse, Bronx, NY 10453

Intake: 212-665-1860

Postgraduate Center for Mental Health is dedicated to serve the housing and the mental health needs of individuals and families. The Postgraduate Adult and Child Clinic provide affordable community based mental health treatment for adults, children from ages 5 and up, adolescents, and families. The Center for Adult Psychotherapy offers comprehensive mental health services for individuals with history of chronic mental illness. Services include individual and group therapy as well as medication management. Medicaid is accepted.

**Tremont Neighborhood Health Action Center**

1826 Arthur Avenue, Bronx, NY 10457

Phone: 718.508.0678/718.508.0618 (call) or 646.531.8660 (text)

The Neighborhood Health Action Center uses a holistic approach to primary care, activates spaces for community organization and planning, and connects residents to neighborhood-based social services. You can go to an Action Center for primary care, mental health care, dental care (in some cases), and referrals to a network of local services, health and wellness classes, workshops, and activities.

**The Bronx Defenders**

360 East 161<sup>st</sup> Street, Bronx, NY 10451

Phone: 718.838.7878

Legal Emergency Hotline: 347.778.1266

The Bronx Defenders provides both legal and non-legal assistance. Open-door community intake services are available to walk-in clients Monday through Friday 9am-4pm. Services include meeting with an advocate to receive an assessment of your issues and needs, and a meaningful referral for services. Services include criminal defense, family defense, immigration defense, housing defense, and access to public benefits such as childcare, healthcare, and transportation.

## All Boroughs

### **BrightPoint Health**

Several locations spread throughout the 5 boroughs.

Intake: 855-681-8700

Primary health care center and behavioral health services available. The behavioral health staff is comprised of licensed clinical social workers, psychologists, psychiatric nurse practitioners and psychiatrists. Brightpoint Health counseling centers are New York State Office of Mental Health (OMH) licensed Article 31 facilities. Services are available in English and Spanish for both adults and children. Medicaid is accepted.

Services include:

- Medication management
- Crisis intervention
- Psychotherapy (individuals, families, and groups)
- 24/7 hotline access
- Evaluations for housing assistance

### **The Jewish Board for Family and Children Services**

15 clinics in all five New York boroughs

Intake: 1.844.ONE.CALL (1844-663-2255)

The Jewish Board has 15 mental health clinics spread throughout the boroughs of New York City, which are open to all New Yorkers in need. The agency provides individual, couples, family and group therapy, as well as evaluation, assessment and medication management. Staff is comprised of psychologists, psychiatrists, social workers and case workers who are equipped to address a wide range of emotional and social problems such as trauma, depression, attention deficit disorder (ADD), domestic violence, anxiety, depression and isolation.

A wide variety of languages are offered from Spanish and Russian to Farsi and Haitian Creole.

Accepts Medicaid and other forms of insurance and offer a sliding scale fee for the uninsured.

### **Safe Horizon Domestic Violence Services**

24-hour Hotline: 800.621.HOPE (4673)

Email: [help@safehorizon.org](mailto:help@safehorizon.org)

Citywide Helpline: 855.234.1042

Safe Horizon offers personalized, non-judgmental, confidential support. They can talk to you about your safety, provide community-based resources, and connect you to their programs and services. Services include crisis counseling, safety planning, and assistance with finding domestic violence shelters.

# Sample Training Content

# SMM Qualitative Study Training Session

## In-Depth Interviews in the Context of Severe Maternal Morbidities



Developed by

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**Christine Morton, Ph.D.** [christine@christinemorton.com](mailto:christine@christinemorton.com)

## Overview of the Day



### Morning

- Connecting with Colleagues
- In-depth Interviewing
  - Methodological goals and strengths
  - Best practices
- Distress Protocol

### Afternoon

- SMM Study protocol
- Specific Best Practices for SMM In-depth Interviews
- Practice Interviews on SMM “participants”
- Feedback & Conclusion

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## [Warm-up/Ice-breaker]



3

## Interview a Colleague



- Write down one single-barreled, open-ended question that you can ask someone which would generate an answer that would help the rest of us get to really know that person.
- Pair up and interview this person by asking their name and then your question.
  - Take notes and try to write down verbatim quote of their answer
- Introduce this person by sharing your ‘findings’ with us.
  - Share with us, why did you choose the question you asked?
- After everyone shares, we’ll go back around and share which question you think gave you the best insights into the person interviewed
  - Why?
  - What made this question so effective?

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## In-depth / Semi-structured Interviews



“...if executed well, brings us arguably closer than many other methods to an intimate understanding of people and their social worlds.”

- Facilitate narrative: help individuals tell their stories
- Interviews tell an individual and a collective story
- Ethnographers use in-depth interviews to gain an understanding of a particular culture or way of being
- Developing rapport - a sense of connection between the participants – is key to eliciting stories
- You may slightly modify the order and wording of questions
- You may ask respondents to elaborate or clarify their answer
  - All respondents may not understand or interpret questions in the same way
- Audio goal: less of your voice, more of theirs – avoid interrupting, unless they’ve completely misunderstood your question.

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## Interview “Guide”



Semi-structured: open to following their train of thought, unless it goes too far off the rails. ...then tactfully redirect.

- That’s really interesting, but I can’t stop thinking about when you mentioned [...] – can you tell more about [...]?”

Too abrupt or often redirection → participants feeling “flustered”:

- Often, guiding them through a chronological recounting of events – from farthest in the past to the present – will prevent them from feeling that they just want to finish this interview as soon as possible.
  - If participant jumps over important part of their story, “*That’s really interesting. Can you take me back to when you first noticed/felt/said []?*”

Try Weiss’s technique to ease transitions between interview guide topics or redirections back to the interview guide:

- Nod affirmation and then say, “Okay, now there’s this other issue I want to ask you about...”

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## Types of Questions



- Our project's interview guide contains both main questions and follow-up questions.
- We separate these because we never want to ask double-barreled questions – just one question at a time to help the participant respond to each question.
- Almost all of the significant questions are worded as open-ended questions – to not allow yes/no or brief answers.
- However, probes are often needed to get more detailed “concrete descriptions” of participants’ observations, thoughts and feelings.
- Our goal is get as ‘thick’ a description as possible, one that allows you to easily imagine – see, hear, feel -- what they went through.
- Consider asking a probe like, “Can you describe the order in which that happened?”

## Language & Question Wording



- Language – “know the language of your interviewee”
  - Why not use medical or academic language?
- Avoid emotional wording in questions
  - What's wrong w/ directly asking “Why?” or “Do you ever...?”
- For example, it's better to ask “About how many times a week do you fib or tell a little lie?”” then to ask “Do you ever lie?”
- What is a double-barreled question?  
*[2 issues in 1 question – example? Avoid asking long, involved questions]*
- Question Sequencing:
  - Does the order of questions matter?  
*[Yes, more sensitive questions should come later in the interview.]*
  - Begin mild/non-threatening, then build up to more complex or sensitive questions.
- The “self-correcting interview”: with your input (via debriefings)
  - We may revise interview guide based on what worked/didn't work in previous interviews

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## The Dramaturgical Interview



*The interviewer can change roles during an interview...*

### Interviewer Roles and Rapport

- Interviewer as Actor (acting as if you are sincerely interested and never shocked or upset)
- Interviewer as Director (keeping the conversation on track)
- Interviewer as respectful Student (interested in learning from participant)
- Interviewer as Storyteller (teller of **collective** stories)
  - Clarifying that this participant's story will be studied along with others like her to see what parts of childbearing experiences are similar to and different than others in the study),

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## Preparing for the Interview



Interviews will be scheduled for the participant to expect a minimum of 1 and maximum of 2 hours

- We don't want to the participant to feel rushed if they start answering questions and realize they have a lot they'd like to share.

Dress in a manner that conveys professionalism but not elitism

Speak and act in a manner which portrays confidence, control of emotions, and convey appropriate level of warmth towards the participant (given that you're likely meeting for the first time).

Know your questions – don't need to have them memorized but be very familiar with them.

Check your digital audio-recorder (fully charged or new batteries)

Also, bring "notes" formatted copy of interview guide and two copies of the informed consent form.

Finally, make sure to bring the compensation

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## Building on Weiss’s “good interviewing partnership”



Goal = collaborate with the participant to produce data that will be useful to the study:

1. Interviewer and participant are working together to produce useful information for the research project.
2. The interviewer will guide the conversation, and the participant will share their experiences and opinions.
3. To make sure all important information is included, the interviewer may ask the participant to share sensitive information.
4. The interviewer will signal nonjudgmental acceptance – verbally and/or nonverbally, as is most natural for each exchange – of all information shared by participant.
5. The interviewer will reassure participant of confidentiality: before, after and (if needed) during the interview.

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## Conducting the Interview



- Keep it conversational – you’re allowed to ‘go with the flow’ and following their tangents, as long as they don’t stray too far away from key topics
- Take notes: nonverbal communication/reactions and key quotes (those that strike you as exceptionally evocative of SMM experiences and/or capture the uniqueness of that participant’s experiences)
- Be an active listener: express appropriate nonverbal communication (head nodding, smile, show appropriate expressions of concern, “mmm hmm”): avoid looking or sounding shocked, upset, frustrated

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## Managing Awkward Moments



- “...the research interview is not a natural communication exchange” – why not?
- We normally have an “intrinsic respect for others’ avoidance rituals,” but we should not always do this during interviews – why not?
- “...maneuver around participant’s avoidance rituals in a manner that neither overtly violates social norms associated with communication exchanges nor causes the subject to lie”
- Note: if a participant ever responds to a question or probe by saying something like, “*I don’t want to talk about that,*” then you should respect their refusal and move onto the next question.

If they become emotional (but not so emotional that the situation requires *Mental Health First Aid*), then offer tissue (always bring a travel-size Kleenex with you) and offer to pause the interview:

- “I’m sorry, I know this is really hard to talk about – would you like to take a break? I can pause the recorder.”

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## The Interviewer’s Repertoire



- *What attitude should you have when conducting an interview?*
- *How do you plan to persuade your participants to give complete/detailed answers?*
- If the participant seems to have stopped short of giving you a complete answer, then echo back one of the last things shared. For example, “So, you felt like they weren’t listening to you...” [pause and try a 30-second ‘uncomfortable silence’ to see if that motivates them to fill in the blanks.]

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## Techniques to Encourage Detailed Answers



**Uncomfortable Silence:** allow long, silent pause after each question

- A participant's natural reaction will be to say something after a 45 seconds or less of good eye contact

**Echoing:** a type of active listening in which you repeat back their main point in slightly different words to show you heard them – they'll often expand their comments. (see following example)

*Jack: "When I first tried using marijuana, I felt really scared. I was really out of control. I didn't like how I felt. I was all alone and I really didn't like how I felt."*

*Do you think Jack used marijuana again?*

*Interviewer: "That must have been a scary feeling."*

*Jack: "Yeah. I wasn't really interested in trying marijuana again too soon. At least I wasn't going to do it alone. I figured it would be better with a group of friends."*

**Letting People Talk:** avoid interruptions unless your participant gets way off target or you need to clarify a particular point...

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## Concluding the Interview



Thanking them for their time, reminding them that their participation will help many other women and families

- Give them their compensation

How do you know if the interview you conducted was "good" or "great"?

- The participant shared rich details with you, and you realize that they shared their inner experiences and took you into their social world.
- You maintain a "sense of equality" but convey "authority over how the interview will run".

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## Critiquing a Sample Interview



As we view the following interview, take notes on where you think the interviewer could have improved their ability to collect good data:

### [Demo Interview](#)

Create a list and discuss:

- By lessening participant's trust/confidence in them
- By damaging rapport, leaving participant feeling like they're not listening to them or, in some way, not valuing what they're saying
- By failing to probe or follow-up in a way that would have improved the quality of the interview data

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## The 10 Commandments of Interviewing



1. Interview in a comfortable place:
  - Usually private, quiet, and of the participant's choosing
2. Always pre-test your equipment and make sure you have all materials:
  - Take notes, in addition to audio-recording each interview
3. Think about appearance:
  - Dress appropriately, in a way that puts respondents at ease
  - How might your social and physical characteristics affect the interviews?
4. Know Your Audience:
  - Use appropriate vocabulary/terminology
5. Never begin an interview cold:
  - Start with small talk, then informed consent, and then throw-away questions or mild demographic questions
6. Remember your purpose:
  - Keep them on track – have your outline in sight

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## The 10 Commandments of Interviewing (continued)



7. Present a natural front:
  - Have questions somewhat memorized so you appear relaxed
8. Demonstrate “active listening”/”aware hearing:”
  - Give appropriate nonverbal responses
  - What if some of what you hear is painful or upsetting to you?
  - What if the respondent becomes visibly upset?
9. Don’t be satisfied with monosyllabic answers:
  - Use probes or “uncomfortable silences”
10. Be respectful, cordial, and appreciative
  - Assure them that you value their opinions/stories
  - If needed, remind them of confidentiality
  - Thank the participant before you begin and after you stop recording

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## [Distress Protocol]



[This could be a good place, at the end of the morning session, for a member of the NYC team to review Distress Protocol]

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**\*\*\*Lunch Break\*\*\***

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## **Overview of Pre-Interview Methodology**



- [Educating the hospital staff]
- [Approaching participants in hospital]
- [Securing their Permission to Contact Form]
- [Calling/texting potential Participants]
- [Scheduling specifics of interview: location, time, etc.]

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## Closeness & Distance in the context of SMM Interviews



- Traditional researcher role → distance & hierarchy
  - Pros and cons for research?
- Interviewer reciprocation, self-disclosure
  - If relevant, not best to talk about your own birth experience, but you may find it helpful to talk about having been a doula or informally assisted with [#] births.
- Presenting the appearance of similarity can also aid in developing rapport
  - “We’ve talked to many women who have experiences like yours”
- Structured does not work well when researcher = very different from participants
- You must be able to make the person feel comfortable and trust you
  - Using a “doula voice” can be helpful; paying close attention and echoing what they tell you

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## In-depth Interviews in the context of SMM



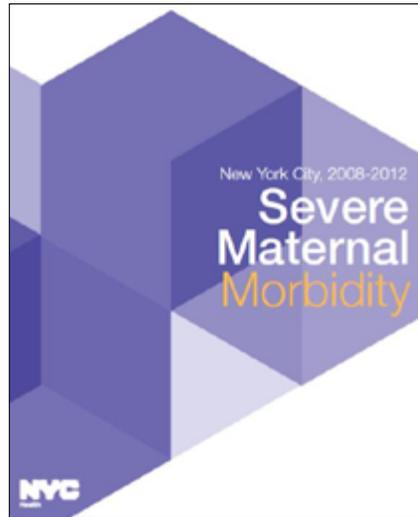
SMM = Severe maternal morbidity, or severe complication related to pregnancy or childbirth; this study defines SMMs as...

- Blood transfusions: 4 or more units
  - Clinical conditions: hemorrhage (bleeding more than 1000 mls) or severe anemia (low red blood cell count)
- ICU admission: could mean different serious health conditions
  - Hypertensive event (seizure, stroke)
  - Organ failure (e.g., liver, heart)
  - Pulmonary (blood clots)
  - Sepsis (including all serious infections)
  - Hemorrhage (severe bleeding)
  - Surgical complications
  - Anesthesia complications
  - Other severe physical complications

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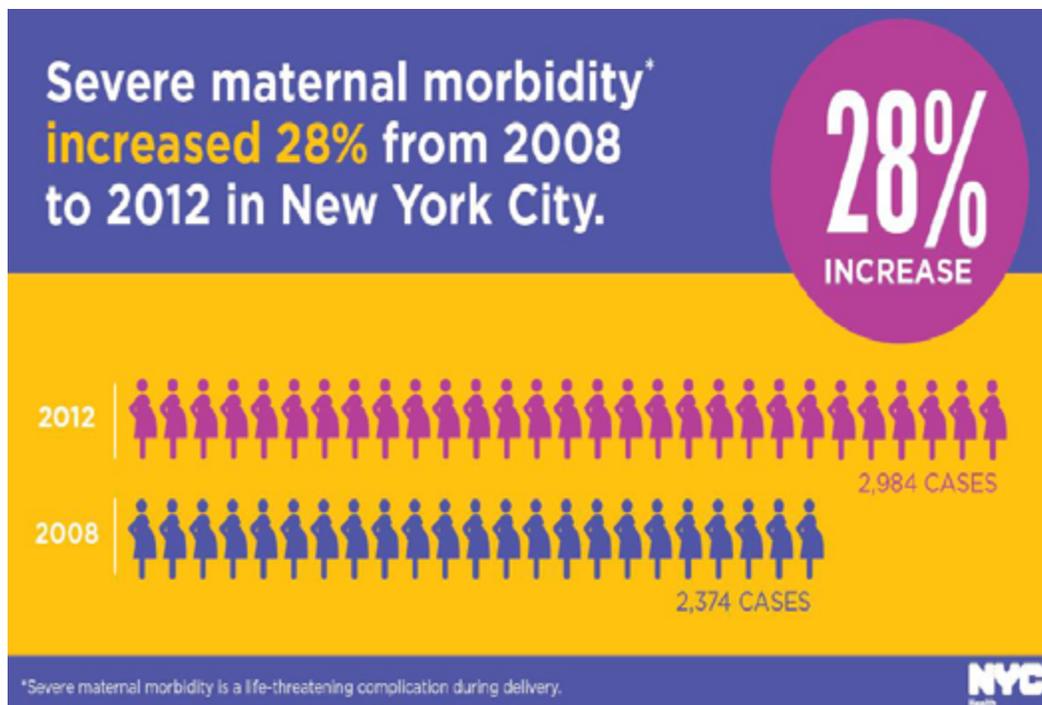


# SMM: Select findings



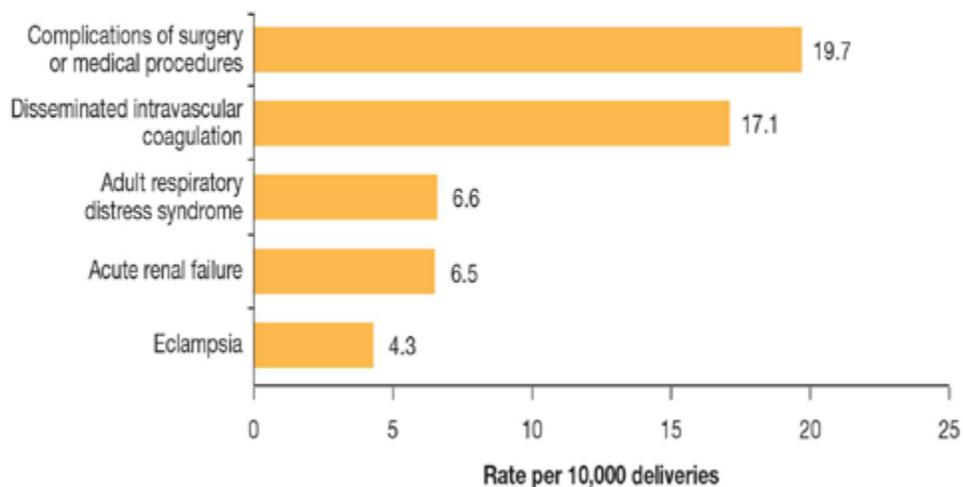
Source: New York City Department of Health and Mental Hygiene (2016).  
Severe Maternal Morbidity in New York City, 2008-2012. New York, NY.

25



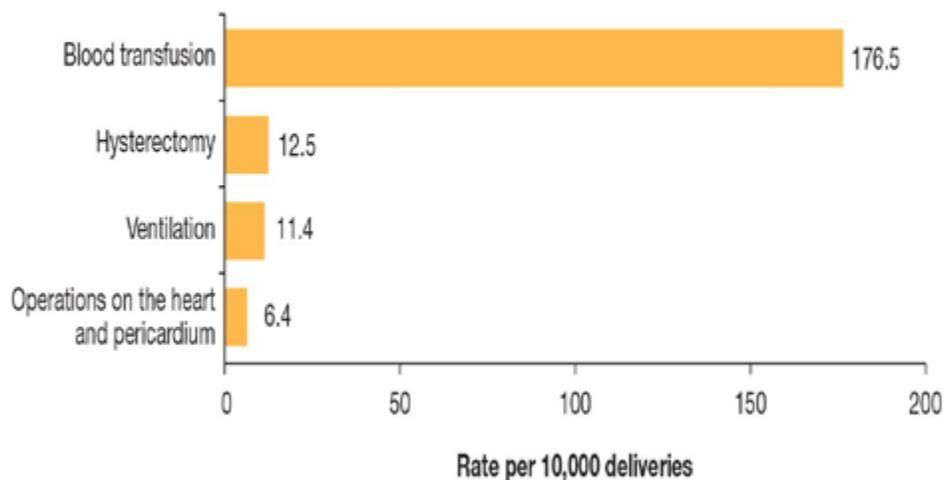
26

**Figure 5. Leading Diagnosis-Based Indicators of Severe Maternal Morbidity, New York City, 2008–2012**



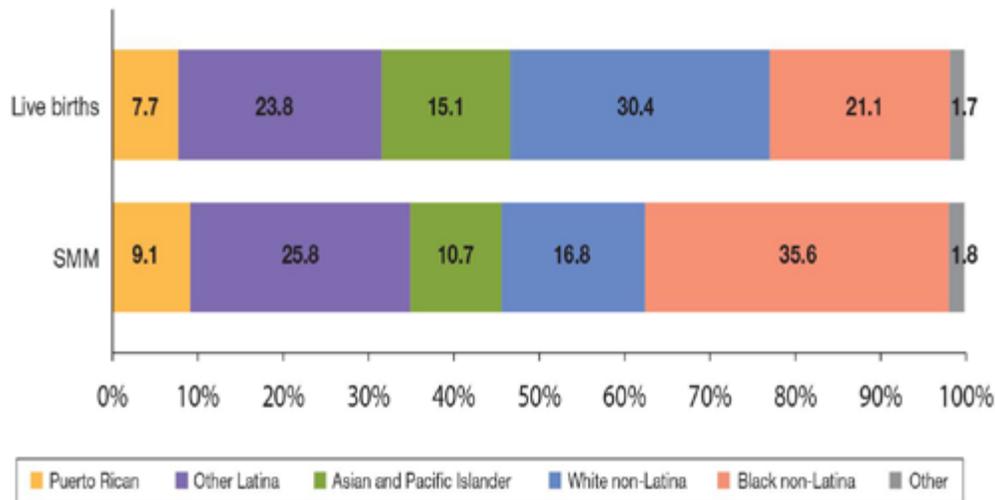
27

**Figure 6. Leading Procedure-Based Indicators of Severe Maternal Morbidity, New York City, 2008–2012**



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Figure 11. Distribution of Live Births and Severe Maternal Morbidity Cases by Race/Ethnicity, New York City, 2008–2012



Severe maternal morbidity\* increased 28% from 2008 to 2012 in New York City.

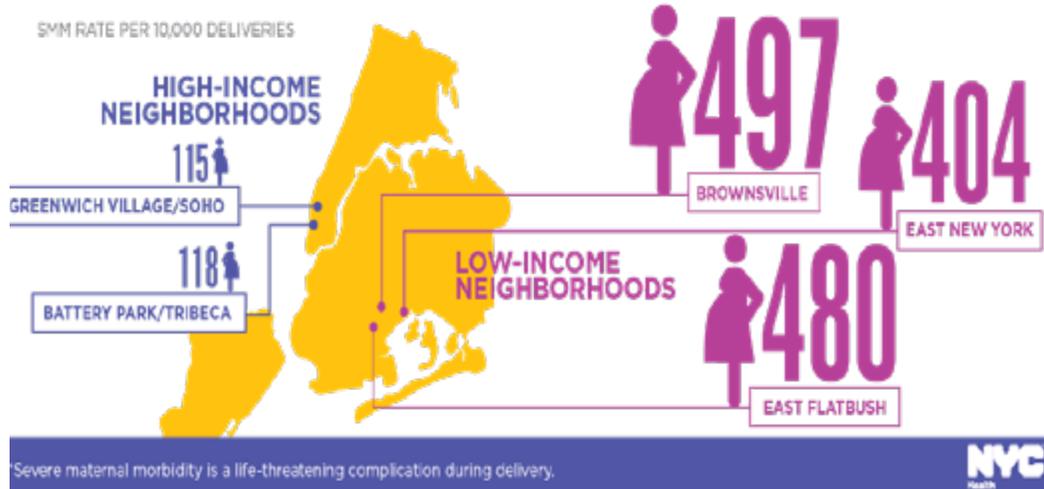
28% INCREASE



Severe maternal morbidity is a life-threatening complication during delivery.



Low-income neighborhoods had the **highest** severe maternal morbidity<sup>7</sup> rates compared to high-income neighborhoods.



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## In-depth Interviews: *The Value of the SMM Patient's Point of View*



For many women, an SMM is an UNEXPECTED feature of their pregnancy/childbirth experience

- Normal postpartum can be challenging for many new moms/parents
- Postpartum PLUS physical/emotional recovery from physical trauma is challenging, even in the best of circumstances
- Talking about their experience can be healing AND also emotionally demanding
- Sample Stories

Typical scenarios of SMMs from our first study...

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## WHAT TO EXPECT FROM POST-TRAUMATIC STRESS?



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## WHAT TO EXPECT FROM AN INFECTION?



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## WHAT TO EXPECT FROM AN EMERGENCY HYSTERECTOMY?

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## Questions to Consider when Interviewing about SMMs



- What kind of relationship do you already have with those you are studying?
- How intimate a relationship is desirable?
- What might be appropriate for you to self-disclose?
- Is your interview process a method for gaining information or a process of sharing information and creating meanings together?
- How will you explain your role to participants?

Example: "I'm talking with women who've had similar experiences giving birth in local hospitals because you know what it's like. So, I'm going to ask you some questions to help make sure you get to tell your full story."

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## Getting Started Script



“Hi, I’m [first name] with the Maternal Health and Well-Being study from the New York City Department of Health and Mental Hygiene.”

- *Sharing personal and/or professional history may lead to stereotypes*

“When you gave birth, someone at the hospital spoke with you about our project, and basically we’re trying to learn about the experiences of giving birth at that hospital because this information will help make birthing experiences as healthy as possible for moms and their babies.”

- “I’ve brought a digital voice recorder because your experiences are important for the study and we want to make sure we get all of your details correct.”
- “But no one will listen to this recording except for the few people who are part of this project.”
- “A professional will type up what we say, and then this audio-recording will be destroyed.”

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## Informed Consent Script (Always bring 2 copies of the form)



“Even though I’ll be recording our conversation, we won’t be using your real name in anything we share about this project.”

“So, even if we use something you say to help people understand childbirth experiences, we won’t use your name or any other identifying information.”

“That’s how we protect your confidentiality, and that’s a main part of the information in this informed consent form.”

“Can you read this over and let me know if you have any questions?”

“Can you sign one copy? The other copy is for you to keep.”

“Your participation is voluntary, so you don’t have to answer any questions, and we can stop the interview at any time.”

“When our interview ends, you’ll receive the gift card and Metro card.”

“Is okay for me to begin recording our interview, or do you have any questions before we begin?”

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## Conducting the Interview in the context of SMM



- It's natural/'typical' for many women to share childbirth experiences
- It's not 'natural' in that we are not their friends or loved ones and we do not judge or evaluate or 'fix' them
- It's also not 'natural' in that we're asking them to share private matters for research to help the public
- Asking about sensitive topics increases vulnerability:
  - Experiences as a vulnerable patient
  - Sexual and reproductive health
  - Intimate family relationships
- We need to "respect and identify avoidance rituals" in these interviews
  - How do we do that with sensitivity?
- Goal: interviews help not hinder healing (not re-traumatizing)

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## Probes to Illicit Detailed Answers



Clarifying who was where, when:

- If unclear who all was involved, "Who else was there when that was happening?"
  - Whenever asking for clarification about others, make sure to check their position/role if not clear: example, "So was that your Ob-Gyn who checked on you after your epidural?"
- "About how much time passed between [...] and [...]?"
- "Sounds like there was a lot going on at that time -- what exactly happened when [health issue or interpersonal conflict arose]?"
- If unclear who said what, "So, did you tell the doctor [...]?"
- If unclear what happened next, "So, what did s/he say/do after that happened?"

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## Probes to Illicit Detailed Answers (continued)



- If unclear what participant was thinking/feeling, “So, what were you thinking then?” or “So, how did that make you feel?”
- When they express an emotional reaction nonverbally, “It looks like you had some feelings about that...”
  - Or, “Can you remember how you felt when [...]?”
- To explore social support, “Did you let anyone know about [...]?”
- If they’re speaking in generalizations – like “*They never listened to me when I said I was in pain.*” – then, you can follow-up with, “Can you tell me about a specific time: what you said and how they responded?”
- If the participant had a non-SMM childbirth experience before this one and is being vague in her answers, “So, in what ways was [a particular part of the labor/delivery experience] different from the last time you gave birth?”

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## SMM Sensitivity: Listening without Bias & Helping them Share Important Details



Check your assumptions:

- She may or may not view her experience as traumatic
- She may or may not be struggling with mental health challenges (anxiety, PTSD, depression, other)
- What other assumptions might you have about this woman and/or women in her community?

Remember: Postpartum + physical/emotional recovery from physical trauma is challenging, even in the best of circumstances

- Accept their childbirth experiences as being true for them, and don’t worry about technical accuracy
  - If they cannot remember details of clinical interactions: e.g., “I bleed a lot” is a valid data point even if they cannot remember whether or not they received a transfusion or how many units.
- We are focused on the breadth and depth to their experience, including their reactions and their memories of others’ reactions

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## SMM Sensitivity: Respecting Participants' Emotions



Attend to participant's behavior and emotions if they...

- avoid direct answers, may not want to answer, and is not responsive when you rephrase/clarify a question
- express emotional distress (tone of voice or crying), then check in...

How to check in regarding emotional distress:

- With warm concern, confirm their expression of emotions (“I know this is hard”, or “I can see this is upsetting,” )
- Give her time to recover. Offer a tissue (have a box of very soft tissues handy). Validate her emotions. ”It’s ok to cry.”

When to pause interview and then offer stopping the interview:

- If respondent says she cannot continue or appears to be in emotional distress, then clarify that you’re pausing the interview and audio-recording: “Let’s take a break, and I’ll stop recording... [wait about 30 seconds] It’s no problem for us to stop the interview, or I can come back another time if you prefer.”

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## SMM Sensitivity: Concluding the Interview



Keep in mind Distress Protocol and Mental Health First Aid Training:

- If signs of severe emotional distress, then follow those guidelines
- If respondent cannot continue, then conclude by thanking for her time, giving her the MetroCard and \$50 Visa card, and then offer resources/packet provided by project (give brief overview of content)

At the conclusion of a completed interview:

- Thank them for their time, give them the MetroCard and \$50 Visa card, and then offer resources/packet provided by project (give brief overview of content)
- Let them know that their information will help us help hospitals improve care for women who have similar childbearing experiences.

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## The 11th Commandment...Practice!



### Learning Activities:

- Review Informed Consent form and implications for conducting interviews
1. Trainers model best (and problematic) practices, using abbreviated study interview guide
- Debrief with trainees:
    - *Do the questions elicit desired responses?*
    - *Was the language meaningful to the respondent?*
    - *Are there problems with questions – double meanings, double barreled, threatening questions, etc.?*
    - *Was the interviewer sensitive with the probing questions?*
    - *How did the interviewer respond to expression of emotional distress?*
2. Each trainer acts as a sample interviewee for one of the trainees to practice interviewing techniques using questions from guide that were not previously modeled in above activity
- Debrief with trainees

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## After the Interview...



- Submitting the audio file: via/how [?] to [?] by [?] date
- [transcription process, timeline]
- [our access to audio]
- [by what date can we expect transcription?]
- [Debriefing phone call...around how many days after...about how long of a phone meeting]
- [If urgent questions/emergencies come up?]
- [If methods questions come up?]

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