

# Interview Material

## Questions for bereaved parents

### Introduction

- Thank participant for taking part in the interview
- Explain that reason for this research is to understand why a large proportion of people currently decline autopsy and whether new methods of autopsy might be more acceptable.
- Recognise that this is a very sensitive subject matter and I can stop the interview at any time if it gets upsetting. Express sympathy of their loss.
- Can also choose to withdraw from study and delete the audio-recording if you would like.

### Feedback on questionnaire

1. Could I start by just asking you if you had any feedback on the questionnaire?
2. We know this is a very sensitive subject. What were your thoughts about being asked to take part in a questionnaire about this topic?

### Own experience of PM

3. One of the key aims of this interview is to discuss your views about new methods of autopsy, but I wonder if before we speak about that you could you tell me about your own experience of being approached about an autopsy examination.
  - a. Prompt: were you expecting to be approached about it?
  - b. Who approached you?
  - c. What did they discuss?
  - d. What type of autopsy were you offered (standard, MIA, NIA, compulsory)?
  - e. Were you given any written/printed information?
  - f. How much time did you have to think about it?
4. Did you agree or decline autopsy? Could you describe your reasons for accepting/declining autopsy?
5. What are your thoughts about how the topic was discussed? Do you have any suggestions for how that discussion could be improved?
  - a. How good/clear was the consent form and other written information?
  - b. Timing of discussion
  - c. Where discussion took place
  - d. The way the information was communicated
  - e. Support in decision-making
6. (For those who had PM) Did you get the information you needed from the PM?

- a. How long did it take to get the results?
  - b. Were they helpful? In what way?
  - c. After the PM, did you see the baby/child? What was that like?
7. Reflecting back on your experience, how do you feel now about agreeing/declining PM?
- a. Has there been any long term impact .g. psychological
  - b. Are these related to procedure itself .e.g invasiveness?
  - c. Impact on having further children
  - d. Any regrets about accepting / declining?

### **Introduce non-invasive autopsy with MRI**

8. What are your thoughts about this new method?
- a. Prompt: is it preferable or not to the standard method?
  - b. What are the advantages?
  - c. What are the disadvantages?
  - d. Views about placenta being taken away for examination?
  - e. Views about baby being in the MRI scanner?
9. Would MIA with MRI be acceptable to you? Why/why not?

### **Introduce MIA with MRI and tissue sampling**

10. What are your thoughts on this method?
- a. Prompt: is it preferable or not to the standard method?
  - b. Is it preferable to the MIA method?
  - c. What are the advantages?
  - d. What are the disadvantages?
  - e. Views on size of cut
11. Would MIA with tissue sampling be acceptable to you?
12. If you had been offered all 3 options, which would you have chosen? Why? Why not the other methods?

### **General**

13. Do you have any other thoughts on these new methods of autopsy, or autopsy in general that you would like to share?
14. Do you have any thoughts about the terminology health professionals should use when discussing investigation after the loss of a baby/child?
- a. Probe: Is the term 'investigation after death' preferable to post mortem or autopsy?

- b. What about the terms I've been using for these new methods such as minimally invasive autopsy and non-invasive autopsy?
- c. Are there any other suggestions you have for the terminology we could use?

15. *For parents for whom compulsory autopsy was required by HM coroner.*

- a. At present compulsory autopsies as required by HM coroner are conducted as standard autopsies. What would be your views on using less invasive methods of examination in these cases?
- b. Do you think a choice of methods (standard/MA/NIA) should be offered to parents in this situation? Why?

# Questions for health professionals and coroners

## Health Professionals

1. Could you start by telling me what you do and your experience talking to patients re autopsy.
  - a. Who would you offer PM to?
  - b. When would you raise the issue?
  - c. Who else discussed the topic with parents?
  - d. What is the hospital policy? What consent form do you use? (do they have a copy)
2. In your experience what are parents views regarding traditional PM?
  - a. What are the reasons they accept?
  - b. What are the reasons they decline?
  - c. What is uptake? Are there any groups more or less likely to consent (religion; stillbirth v Top v neonatal etc)
3. What has been your experience of discussing autopsy with people of different faiths?
  - a. Muslims
  - b. Jews

### ***Describe non-invasive autopsy with MRI***

4. What are your views on this new method?
  - a. Have you any experience of offering it?
5. What do you think would be the views of bereaved parents towards this new method of PM?
  - a. Why might they accept
  - b. Why might they decline
6. Would it be acceptable to parents who currently decline standard autopsy?
  - a. Probe: Parents from particular religious/ethnic groups?
  - b. Any parents to whom it would not be acceptable?
7. Are there any religious/cultural reasons why this new method would be acceptable or unacceptable?

### ***Describe minimally invasive autopsy with MRI and tissue sampling***

8. What are your views on this new method?
  - a. Have you any experience of offering it?
9. What do you think would be the views of bereaved parents towards this new method of PM?
  - a. Why might they accept
  - b. Why might they decline
10. Would it be acceptable to parents who currently decline standard autopsy?
  - c. Probe: Parents from particular religious/ethnic groups?
  - d. Any parents to whom it would not be acceptable?

11. Are there any religious/cultural reasons why this new method would be acceptable or unacceptable?
12. Do you have any experience of discussing MIA/NIA with parents? If YES, what has been the reaction?
13. Do you think for most people these methods would be preferable to standard PM?
14. Which of the 2 methods we've discussed do you think would be preferable to most people and why?
  - a. Why might people prefer Standard PM to MIA/NIA?
15. How do you think doctors could improve the discussion they have with patients in relation to investigation after death?

**General**

16. How do you think doctors might make investigations after death more acceptable to people that are currently likely to decline?
  - a. Probe: Are there things doctors could focus on when discussing autopsy?
  - b. Does the religious/ethnic background of the doctor matter?
  - c. Language of the information/consent form?
17. What education and support needs to be in place for HCPs offering new methods of investigation after death?
18. In what way can we ensure discussions around autopsy are discussed in culturally appropriate ways? What are your experiences with having such types of conversations?
19. When talking about new methods of investigation after death, what term do you think is most appropriate, non-invasive autopsy, less invasive autopsy or investigation after death? Are there any other suggestions you have for the terminology we could use?
20. Is there anything else you find helpful when discussing PM?
21. Do you have any further thoughts on any of the issues we have discussed today that you think are important to mention?

**Coroners**

1. Could you start by telling me what you do and your experience talking to patients about PM.
  - a. In what circumstances would someone be required by law to have a PM?
  - b. How do you interact with hospitals regarding child deaths?
  - c. Do you have any contact with parents before or after the PM?
  - d. Would an individual family's requests about PM be considered?
2. In your experience what are parents views regarding traditional PM?
  - a. What are their concerns?
3. What, if any, concerns do you experience from:
  - a. Health professionals
  - b. Religious leaders
4. What has been your experience of conducting PM for people of different faith groups?
  - a. Muslims
  - b. Jews

***Describe non-invasive autopsy with MRI and minimally invasive autopsy with MRI and tissue sampling***

5. What are your views on these new methods?
  - a. Have you had any requests from parents/HPs about using MIA/NIA?
  - b. Have you any experience of using either of them? If so which?
  - c. If yes, in what circumstances did you use MIA/NIA?
  - d. If no, would there be any circumstances when you might consider using MIA/NIA? If yes, when?
  - e. What has been/might be the impact on your work of offering MIA/NIA?
6. Do you have any concerns about MIA/NIA? If so what?
  - a. Would there be any practical/logistical difficulties in using MIA/NIA? (Prompt: availability of MRI scanner)
7. What do you think would be the views of bereaved parents towards these new methods of PM?
  - a. Do you think offering the option of MIA/NIA would make the procedure more acceptable to bereaved parents? If yes, why? If no, why not?
8. Would it make it easier for you if parents were more accepting of PM generally?
9. Do you have any further thoughts on any of the issues we have discussed today that you think are important to mention?

## Questions for religious and community leaders

1. Could you start by telling me a little bit about your religion's view towards PM?
  - a. Religious v cultural attitudes
  - b. Differences amongst different religious sects

### **Describe standard autopsy**

- *Usually involves a procedure like an operation in which all parts of the body can be examined in detail, including the internal organs (lungs, heart etc).*
  - *A large incision is made in the chest and stomach and each organ is then removed and examined.*
  - *Depending on the circumstances an incision may also be made around the head so that the brain can be removed and examined.*
  - *In most cases the doctor will remove a small sample of tissue from these organs to examine later under a microscope.*
  - *The organs are then put back and the incision is closed securely.*
  - *Using this approach, in around 30-40% of cases, additional information is found which may help answer some of the questions above.*
  - *This type of autopsy is considered the 'standard' as it is the usual procedure and may provide most information.*
2. In your experience, have you met or worked with any parents that have lost a child/pregnancy unexpectedly and have been approached by the hospital about an autopsy?
    - a. Respecting confidentiality, can you remember what their experience was and whether overall it was positive or negative?
    - b. What were their reasons for accepting/declining?
    - c. What questions do they ask about PM?
    - d. What response do you give?
  3. Could you describe how your particular religious/cultural community views autopsy?
    - a. Prompt: Are there any religious/cultural reasons why it is acceptable/unacceptable? Removal of organs before returning them to body? Cutting body?
  4. How do you think parents in your religion/community might feel about standard autopsy?
  5. Would families from your community be treated any differently by the community if they consented or declined to standard autopsy?

### **Describe non-invasive autopsy with MRI**

- *Recently, a new type of autopsy has been developed called non-invasive autopsy.*
  - *It does not require any incisions to the body.*
  - *Instead it is based around an examination of the body using a special type of imaging (like an X ray) called an MRI which is non-invasive.*
  - *It can also include examination of the placenta or bloods (blood prick test)*
  - *In some cases this approach alone is not as good as a standard autopsy, mainly because there is no tissue to examine under a microscope*
  - *However, there may still be some cases in which a standard autopsy provides most information.*
6. How do you think parents in your community might feel about this new method of autopsy?

7. Are there any religious/cultural reasons why this new method would be acceptable or unacceptable?
8. Do you think it would be acceptable to parents who currently decline standard autopsy?

***Describe minimally invasive autopsy with MRI and tissue sampling***

- *Another option being developed is to have minimally invasive autopsy which involves imaging as above but also include examination of internal organs and tissue sampling all done using a 'keyhole surgery' technique.*
  - *Requires a small incision (around 10-20mm) to the upper stomach area and a very small camera (like a thin telescope) is inserted into the body which enables the doctor to see the internal organs on a TV monitor.*
  - *Using a fine instrument the doctor is also able to sample small pieces of tissue to examine under a microscope if required. The small incision is then closed securely.*
  - *This type of autopsy is very new and research is still underway to see how reliable it is. However, because organs can be examined and tissue samples are available, it is likely to be almost as reliable as a standard autopsy examination in most cases. Since it's minimally invasive, there are very few marks left on the body.*
9. How do you think parents in your community might feel about this new method of investigation after death I described?
  10. Are there any religious/cultural reasons that you know of why this new method would be acceptable or unacceptable?
  11. Do you think it would be acceptable to parents who currently decline standard autopsy?
  12. Do you have any experience of discussing MIA/NIA with bereaved parents? If YES what has been their reaction?
  13. Out of all the different options we have discussed, which do you think would be preferable to people from your community?
    - a. Probe: If the new methods of autopsy that I have described are both unacceptable, is there any way that autopsy could be delivered in a way that IS acceptable to your community?
  14. How do you think doctors could improve the discussion they have with patients from your community in relation to investigation after death?
    - a. Things they could focus on when discussing autopsy?
    - b. Does religious/ethnic background of the doctor matter?
  15. Do you have any further thoughts on any of the issues we have discussed today that you think are important to mention?



## Focus group topic guide

### Introduction

- Welcome everyone to the group
- Explain reason for being here today
- Doesn't matter if they don't know anything about post-mortem or have never had any experience of having to make a decision about PM, your views and experiences are equally valid
- Some of the things we will discuss today will be very personal. There are no right or wrong answers and I hope you will feel free to express your views and respect the views of everyone else
- I would also ask you to keep all comments made during the focus group confidential and not discuss what happened during the focus group outside the meeting.
- Using a tape recorder to record our conversation because it is difficult for me to write down everything you say and we wish to write up a report of this study to publish in academic journals and a report. Your names and personal details will not be mentioned in any report.
- Please try to speak one at a time so that I can follow what is being said.

Go around room say your name

1. Start by asking if anyone in the room has any experience of PM, either of an adult or a child or baby. Does anyone want to say anything about their experience?

### Discussion around standard PM

- *Following death in childhood, or the death of a baby, either during pregnancy (stillbirth), after birth (infant death) or following termination of pregnancy for an abnormality, many parents want an answer to the question 'why did this happen?', and 'will it happen again?'*
- *In order to try and answer these questions, the doctor may think it would be useful to perform an investigation known as a post mortem examination (also known as an autopsy examination).*
- *This usually involves a procedure like an operation in which all parts of the body can be examined in detail, including the internal organs (lungs, heart etc).*
- *A large incision (cut) is made in the chest and stomach and each organ is then removed and examined.*
- *Depending on the circumstances an incision may also be made around the head so that the brain can be removed and examined. In most cases the doctor will remove a small sample of tissue from these organs to examine later under a microscope. The organs are then put back and the incision is closed securely.*
- *Using this approach, in around 30-40% of cases, additional information is found which may help answer some of the questions above.*
- *This type of PM is considered the 'standard' as it is the usual procedure and may provide most information.*

2. What are your thoughts about standard PM?
  - a. Do you think it is a useful procedure? Why/why not?
  - b. Do you think it is important to offer people PM?
  - c. What do you see as being the main reasons for parents of consenting to PM following the death of a child or baby?
  - d. What do you see as being the main reasons for parents declining PM?
  
3. In your own community, how is PM viewed?
  - a. Is it something acceptable or considered unacceptable?
  - b. Are there any religious or cultural reasons why it might be unacceptable?
    - i. Is there any issue around religious rules
    - ii. Effects on funeral arrangements
    - iii. What if any stigma exists
  - c. Are there any reasons when it might be considered acceptable?
    - i. Multiple loses in same family?
  
4. Who would make the decision in your family about PM?
  - a. Probe: joint decision? Woman? Man? Family? Religious leader? Wider community?

### **Discussion around new methods of investigation after death**

I'm now going to describe new methods of investigation after death that have recently been developed and then ask you some questions about what you think about them.

#### *Non-invasive PM using MRI*

- *Recently, a new type of investigation after death has been developed called non-invasive PM.*
- *It does not require any cuts to the body. Instead it is based around an examination of the body using a special type of imaging (like an X ray) called an MRI. It may also include examination of the placenta or testing bloods to look at genetic causes.*
- *These kinds of imaging techniques on their own can provide highly detailed information without the need for any 'invasive' testing. However, in some cases this approach alone is not as good as a standard PM, mainly because there is no tissue to examine under a microscope so might miss things like infections.*
- *However, in other cases, the detailed imaging may allow the doctors to detect things that are not usually seen at standard PM, so there may be additional advantages as well as disadvantages.*

5. What are your thoughts about this non-invasive method of PM?
  - a. advantages
    - i. Leaves body intact
  - b. Disadvantages
    - i. Timeframe?

- ii. Any concerns around 'imaging'?
6. Do you think this method is acceptable or unacceptable?
    - a. How would it be viewed in the community?
    - b. Any religious reasons why it would be acceptable or unacceptable?
    - c. Would it be acceptable to people who currently decline standard PM?

*Minimally invasive PM with MRI and tissue sampling*

- *Another option being developed is to have minimally invasive PM which involves imaging as above, but also includes examination of internal organs and tissue testing all done using a 'keyhole surgery' technique.*
  - *A small incision (around 10-20mm) is made to the upper stomach area and a very small camera (like a thin telescope) is inserted into the body which enables the doctor to see the internal organs on a TV monitor.*
  - *Using a fine instrument the doctor is also able to remove small pieces of tissue to examine under a microscope if required.*
  - *The small cut is then closed securely and discreetly.*
  - *This type of PM is very new and research is still underway to see how reliable it is. However, because organs can be examined and tissue testing is possible, it is likely to be almost as reliable as a standard PM examination in most cases.*
  - *However, there may still be some cases in which a standard PM provides most information.*
  - *Because there are only very small incisions on the body, this approach may be more acceptable to patients.*
7. What are your thoughts about this minimally invasive method of PM?
    - a. What are the possible benefits?
      - i. Less invasive - doesn't remove organs from body
      - ii. Scan does not tamper with body
    - b. Disadvantages:
      - i. Tissue sampling still requires a cut
      - ii. Still might delay funeral
  8. Do you think this method is acceptable or unacceptable?
    - a. How would it be viewed in the community?
    - b. Any religious reasons why it would be acceptable or unacceptable?
    - c. Would it be acceptable to people who currently decline standard PM?
  9. Out of all the different options we have discussed, which do you think is preferable, if any?
  10. Do you think you might consent to one or more of the options discussed today?
  11. Are there any ways we could make PM acceptable, particularly to people who currently decline?

- a. Probe: Are there things doctors could focus on when discussing PM?
- b. Does the religious/ethnic background of the doctor matter? Why/why not?
- c. What about the language of the information/consent form?
- d. Word 'post mortem' or 'autopsy' or something else?

## **Summary**

The intention tonight was to talk about how people in the community views PM. We've talked about reasons why people might accept standard PM, and the new methods available and whether they might be more acceptable. We've also talked about how doctors might improve the way they discuss this sensitive topic with patients. Have we missed anything? Is there anything else you'd like to add before we finish?

Thank you very much for your time. We are very grateful for all you contributed, we realise this can be a very emotional and delicate issue.