

# Post Mortem imaging: What do families really want?

**Celine Lewis PhD**

17 May 2019

---

North East Thames  
Regional Genetics Service

FUNDED BY  
**NIHR** | National Institute  
for Health Research

Great Ormond Street   
Hospital for Children  
NHS Foundation Trust

Conflict of interest statement:

I have no conflict of interest to declare

# Historically low rates of perinatal PM uptake



## UK perinatal & paediatric consent rates

	Stillbirth	Neonatal death
Offer of PM	98%	81%
Uptake of PM	49%	29%

2018: Draper et al. *MBRRACE-UK Perinatal Mortality Surveillance Report: UK Perinatal Deaths for Births from January to December 2016*

# Study aims

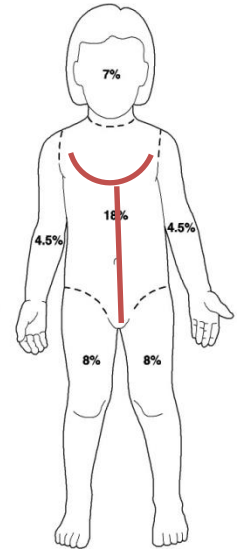
1. Acceptability of different types of PM for bereaved parents
2. Whether less invasive PM is likely to improve uptake rates



**Non-invasive autopsy or NIA**  
imaging only



**Minimally-invasive autopsy or MIA**  
Imaging plus targeted biopsy



**Standard autopsy**  
Organs removed & examined

# Study design

## Survey



### **Description of standard autopsy**

Would you agree to it? *Yes, No, Not sure*

How acceptable is it? *Very acceptable – not at all acceptable*

*Free-text responses*

### **Description of non-invasive autopsy**

Would you agree to it? *Yes, No, Not sure*

How acceptable is it? *Very acceptable – not at all acceptable*

*Free-text responses*

### **Description of minimally invasive autopsy**

Would you agree to it? *Yes, No, Not sure*

How acceptable is it? *Very acceptable – not at all acceptable*

*Free-text responses*

### **Preference:**

standard, MIA, NIA, none, no strong preference

*Free-text responses*

# Study design

## Survey



**Recruitment:** (June 2016 – Dec 2017)

**Retrospective recruitment:** Online through website/FB page of 4 UK support groups

**Prospective recruitment:** Through 6 antenatal/neonatal units

**Inclusion criteria:** Open to anyone who had experienced pregnancy loss (ether miscarriage, ToP for fetal anomaly, stillbirth) or neonatal or infant death irrespective of whether they were offered PM or accepted PM

# Response rate

## Survey



**Total: n=857**

Retrospective: n=789

Prospective: 68

51% free-text comments

# Study design

## Interviews



## Recruitment

**Sample:** Survey responders who indicated they were willing to take part in a telephone interview

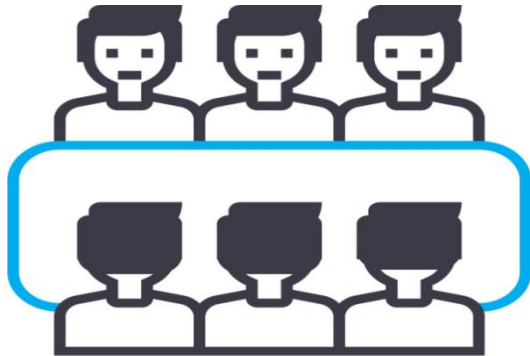
**Variation:** Demographic characteristics, experience of loss, views regarding acceptability of (less invasive) PM

**Uptake:** 20 bereaved parents (56% recruitment rate)



# Study design

## Focus groups with Muslim and Jewish participants



## Recruitment (Sept 2016 – May 2017)

### Sites:

Muslim Community Centres in London and Midlands  
Synagogue in N London  
Rabbi from Ultra-Orthodox community in N London

### Inclusion criteria:

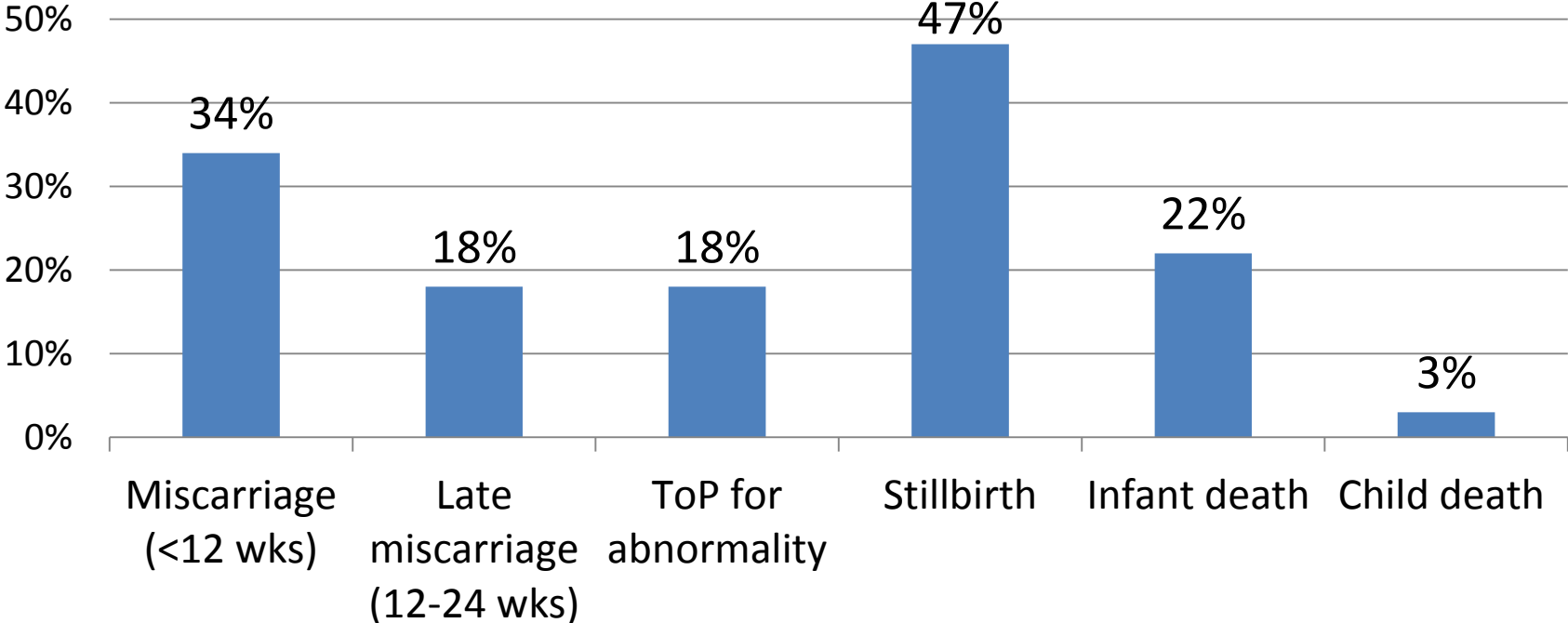
Parents  
Males and females  
Childbearing age (18-40)  
English, Bengali or Urdu speaking (translator present)

### 10 focus groups

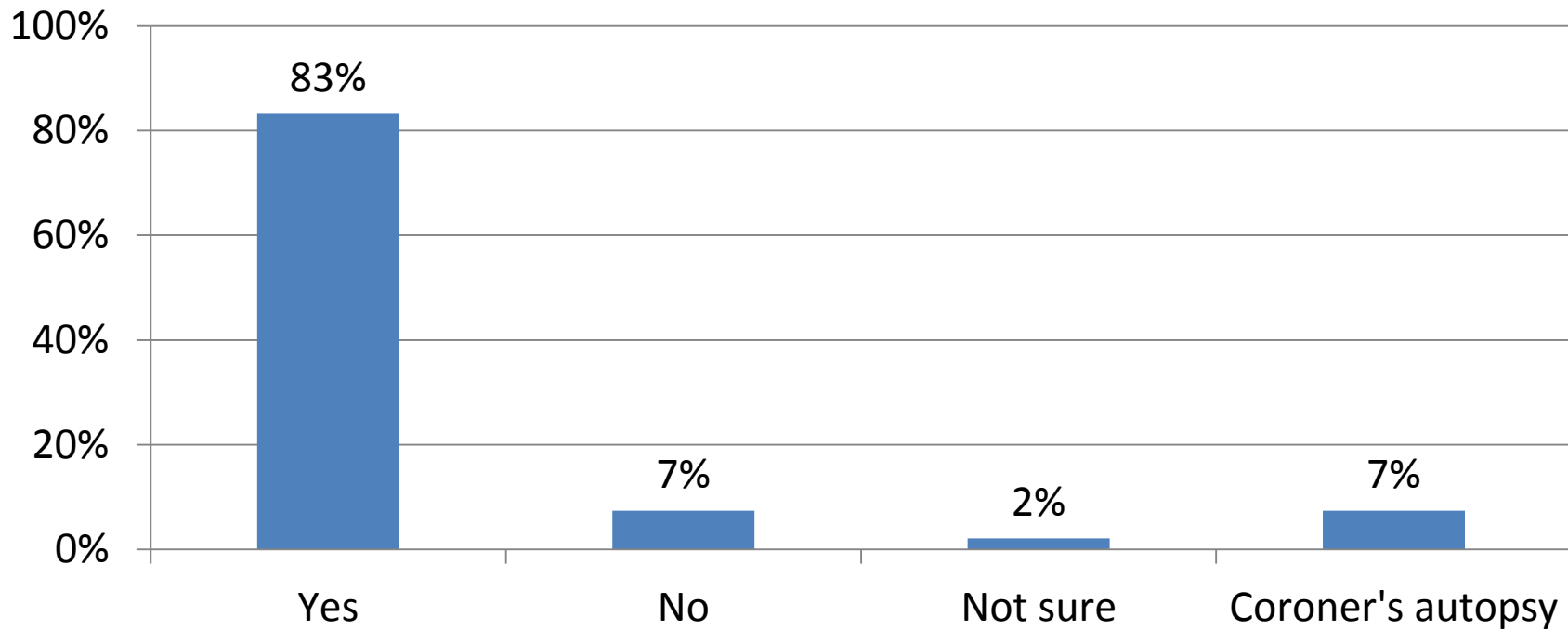
60 Muslim participants  
16 Jewish participants

# Survey responders experience of loss

Mirrors proportions from recent national data

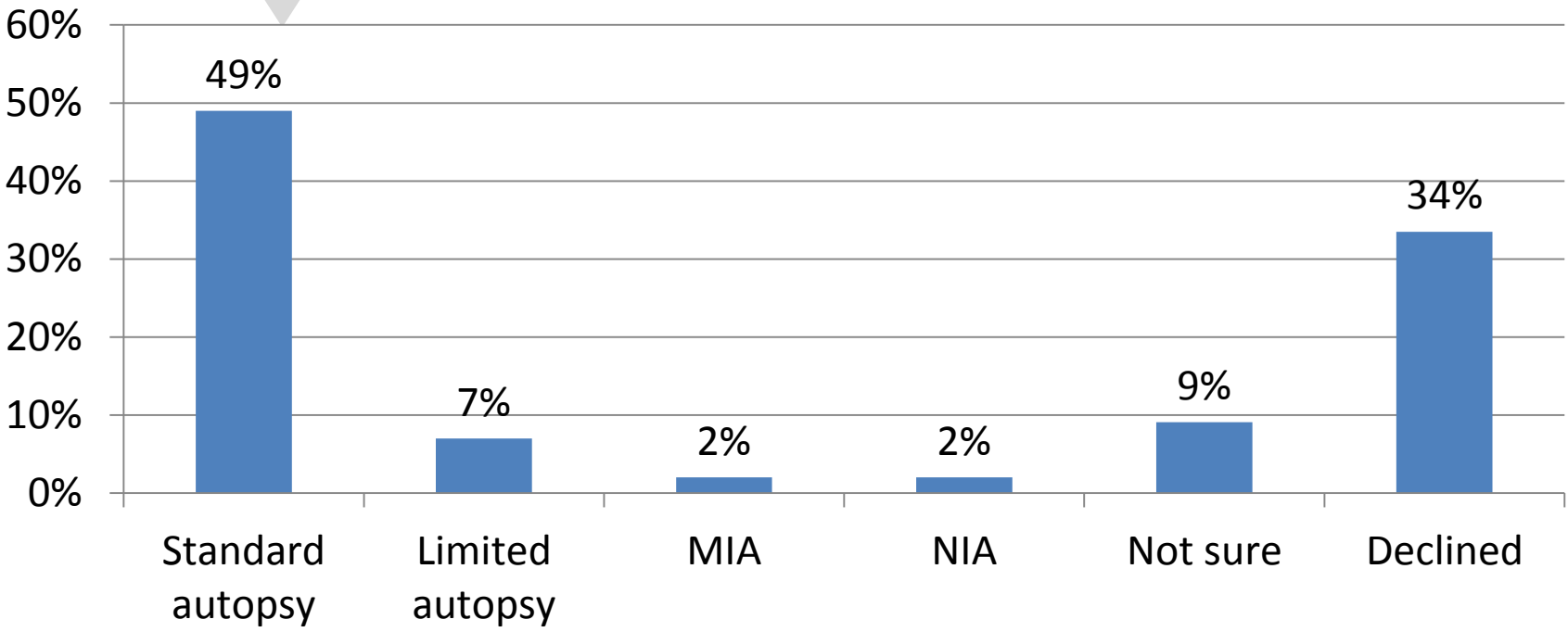


# Were you offered A PM?

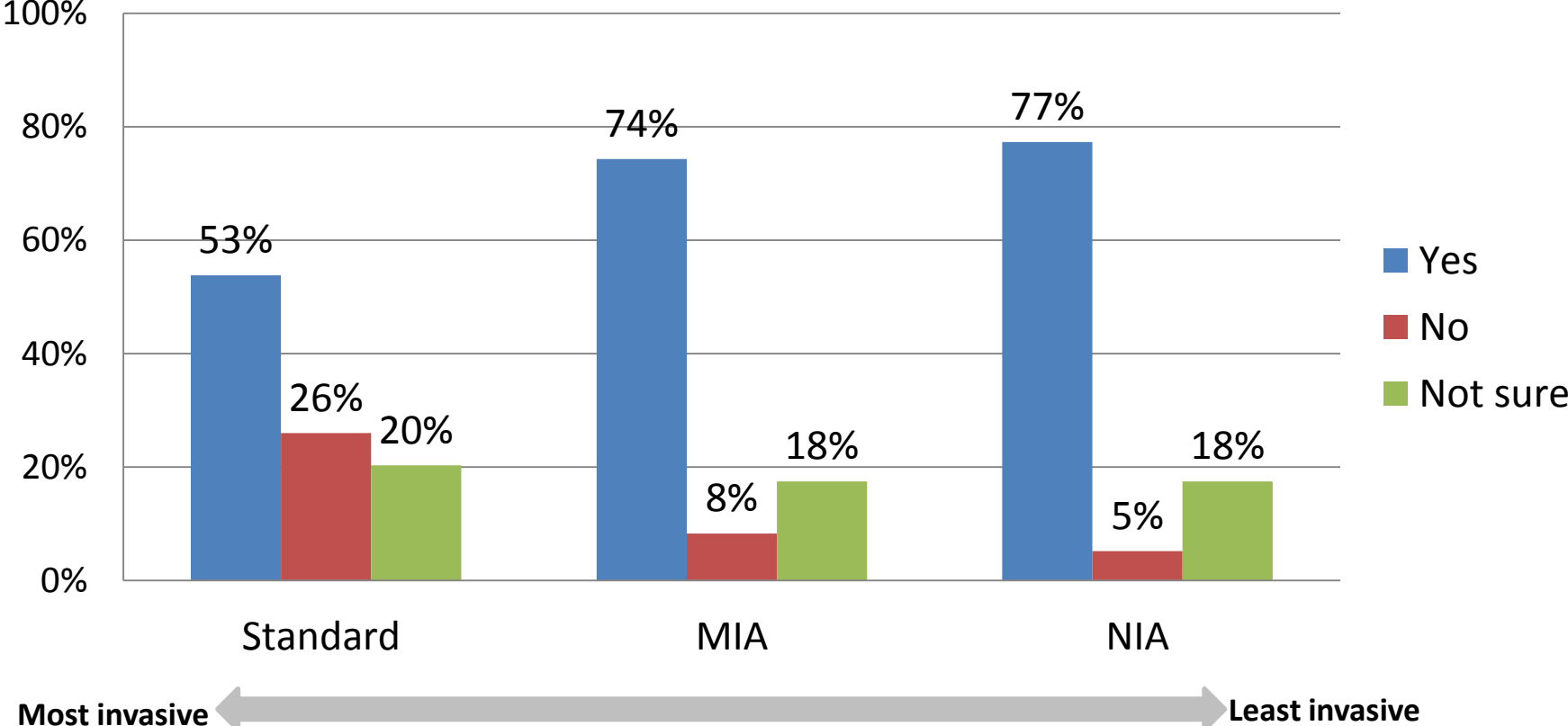


# Did you consent to a PM?

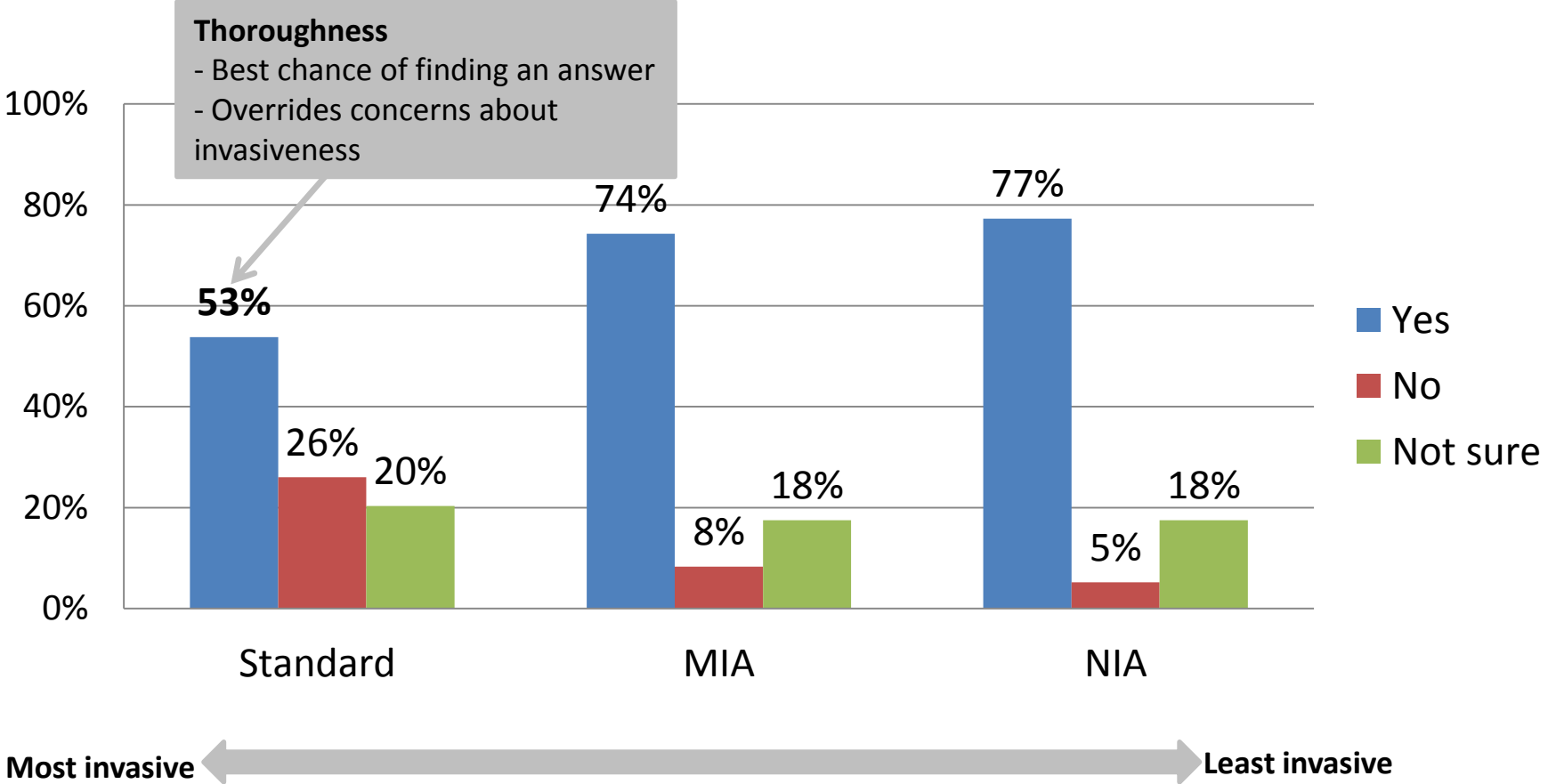
Mirrors proportions from recent national data



# Would you consent to the following types of PM?



# Would you consent to the following types of PM?



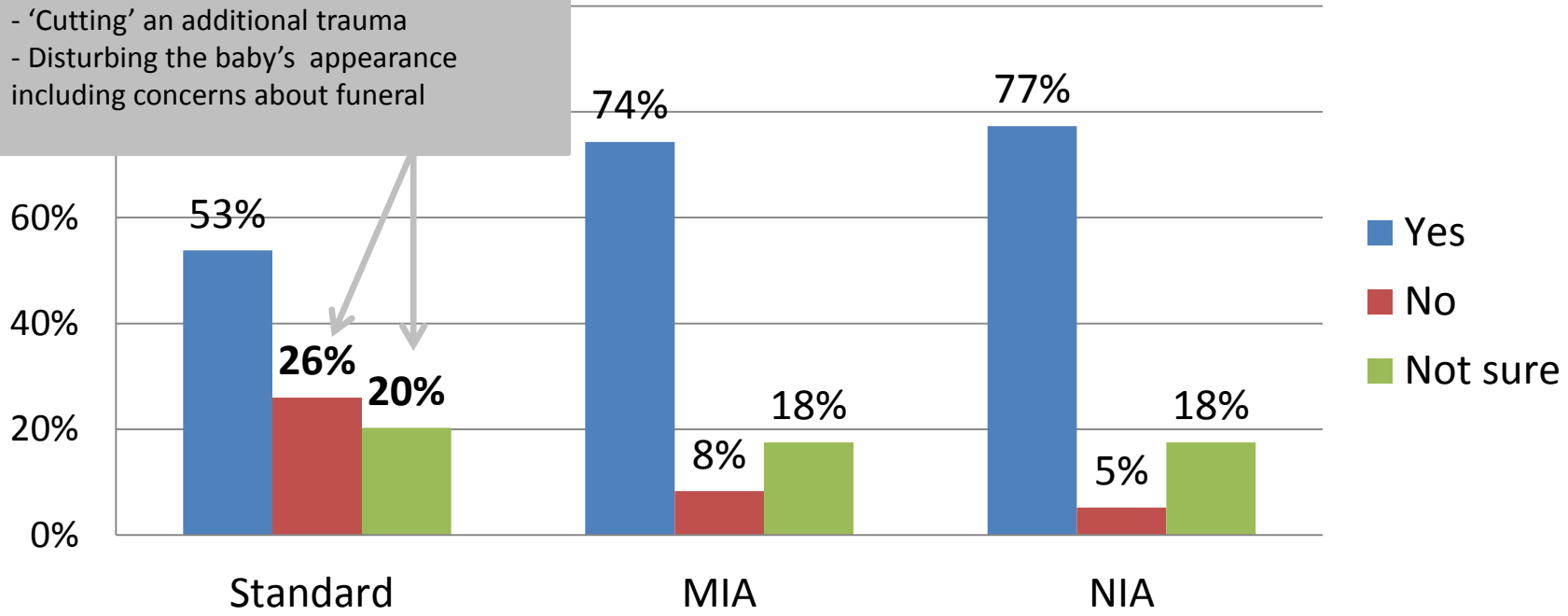
*“I understood that the procedure was invasive on my daughter's body however **it was extremely important for us to understand why she died** after a seemingly healthy pregnancy. It was difficult to think of what would happen to her body however **it was worth this distress to get an answer.**”*

Sands, experienced stillbirth, consented to standard autopsy

# Would you consent to the following types of PM?

**Invasive as problematic**

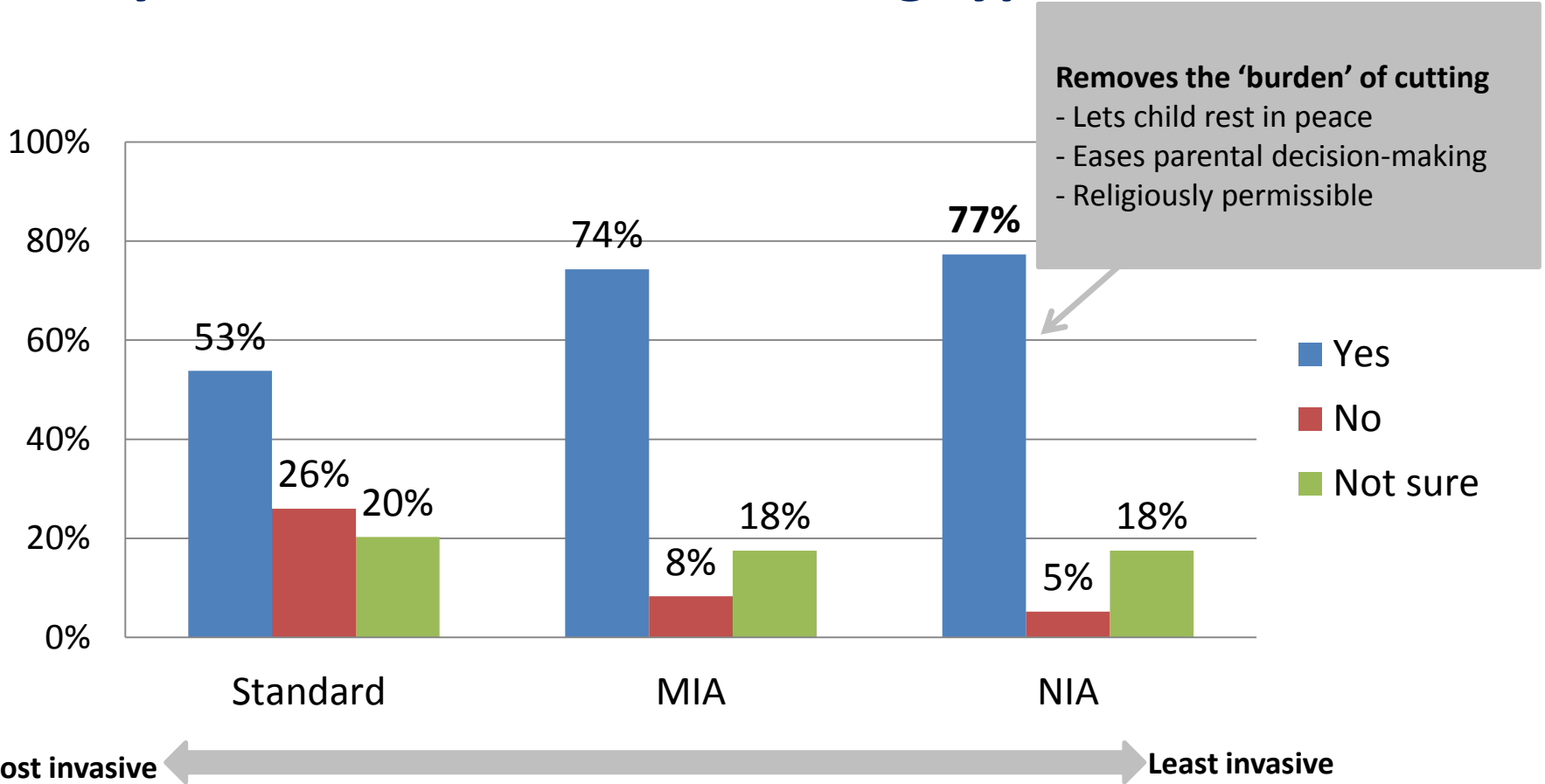
- Prohibited for parents from Muslim/ Jewish faith
- 'Cutting' an additional trauma
- Disturbing the baby's appearance including concerns about funeral



Most invasive ←—————→ Least invasive



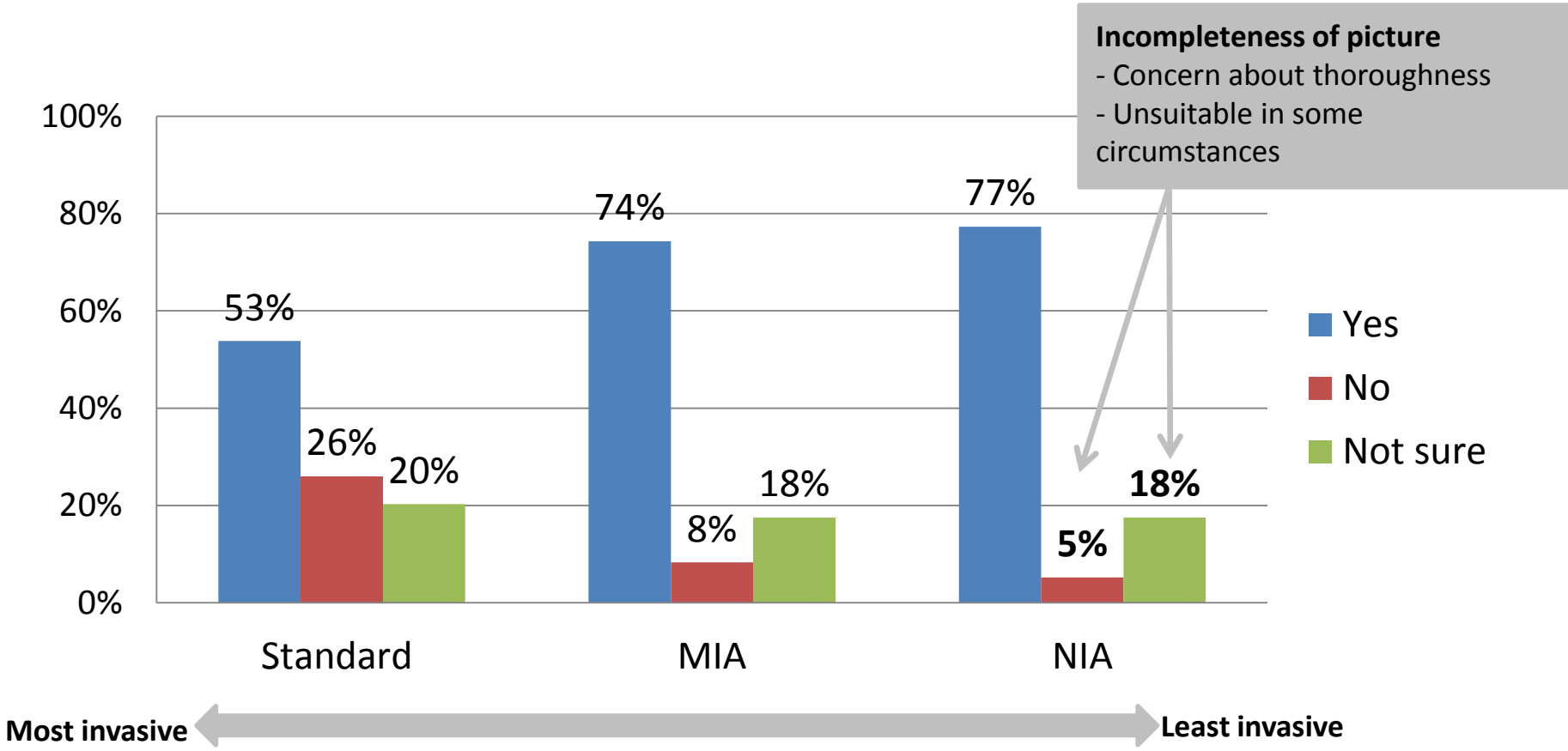
# Would you consent to the following types of PM?



*““My initial thought would be, **absolutely 100% I would go for a non-invasive [autopsy]**, without any hesitation... you’re keeping the body intact.”*

Jewish Orthodox parent

# Would you consent to the following types of PM?

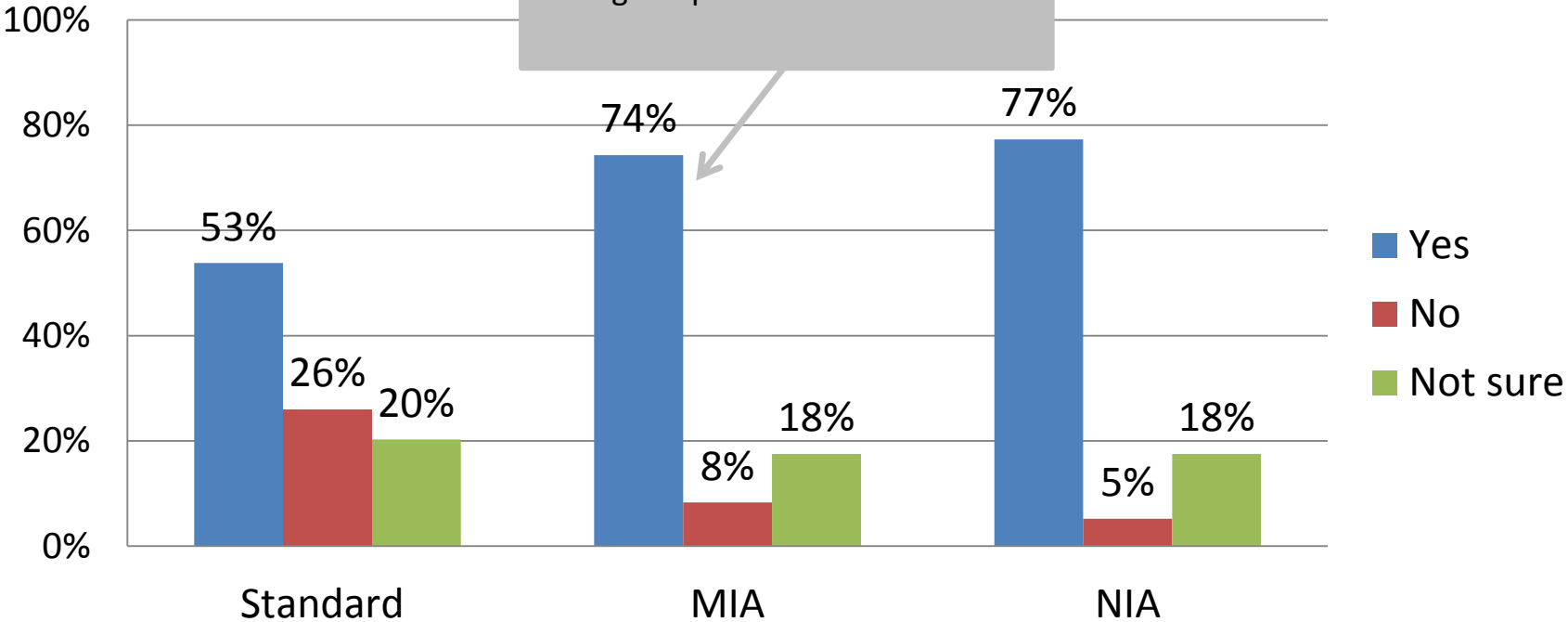


*“A less invasive procedure would have appealed to me at the time. However I felt the need to know everything I possibly could about what was wrong with my baby, so would struggle with the idea that **something might be missed that could have been picked up from a different method.**”*

ARC, ToP and stillbirth, consented to standard autopsy

# Would you consent to the following types of PM?

**Best of both worlds**  
Information with 'desecration'  
Easing the parental burden



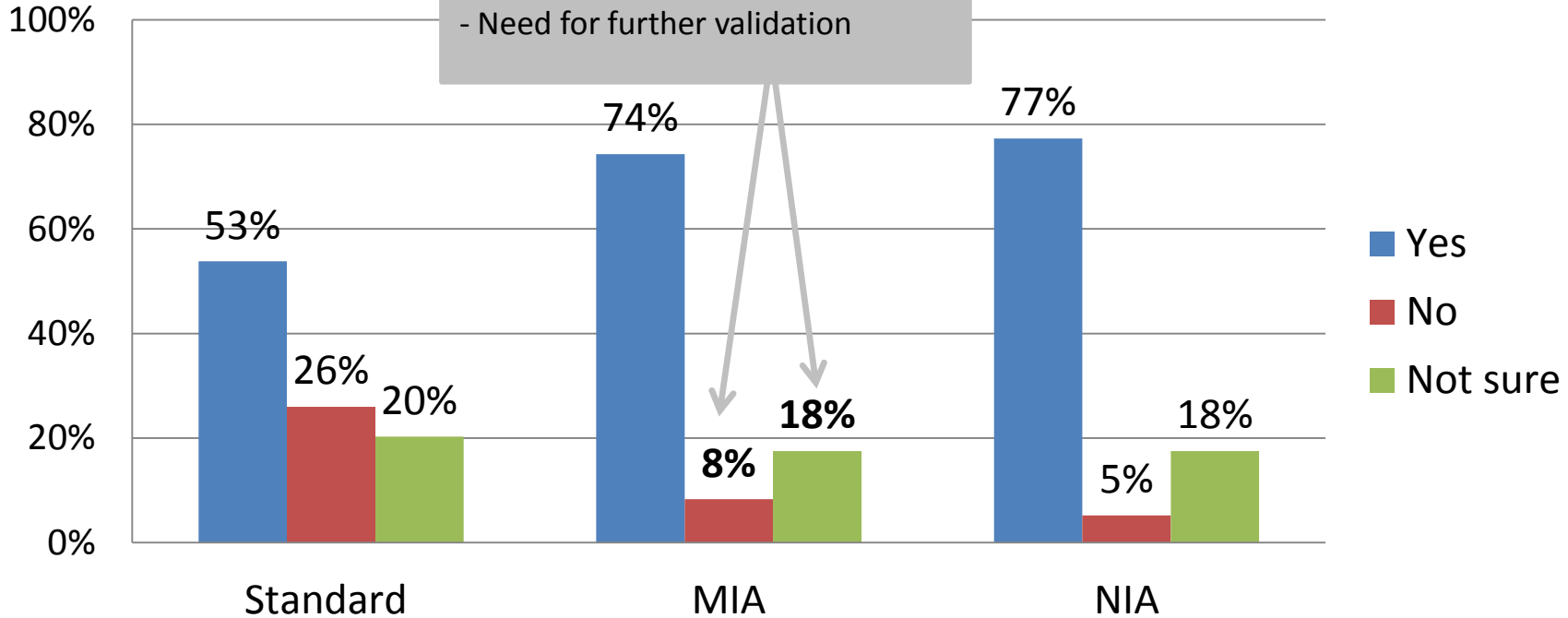
Most invasive ←—————→ Least invasive

*“This seems like the **best of both worlds** - you can physically see organs, and take samples, whilst at the same time being minimally invasive and less distressing for parents to agree to”*

ARC, ToP for abnormality, consented to standard autopsy

# Would you consent to the following types of PM?

**1. Comparability to complete PM**  
- Leaving 'no stone unturned'  
- Need for further validation



Most invasive ← → Least invasive

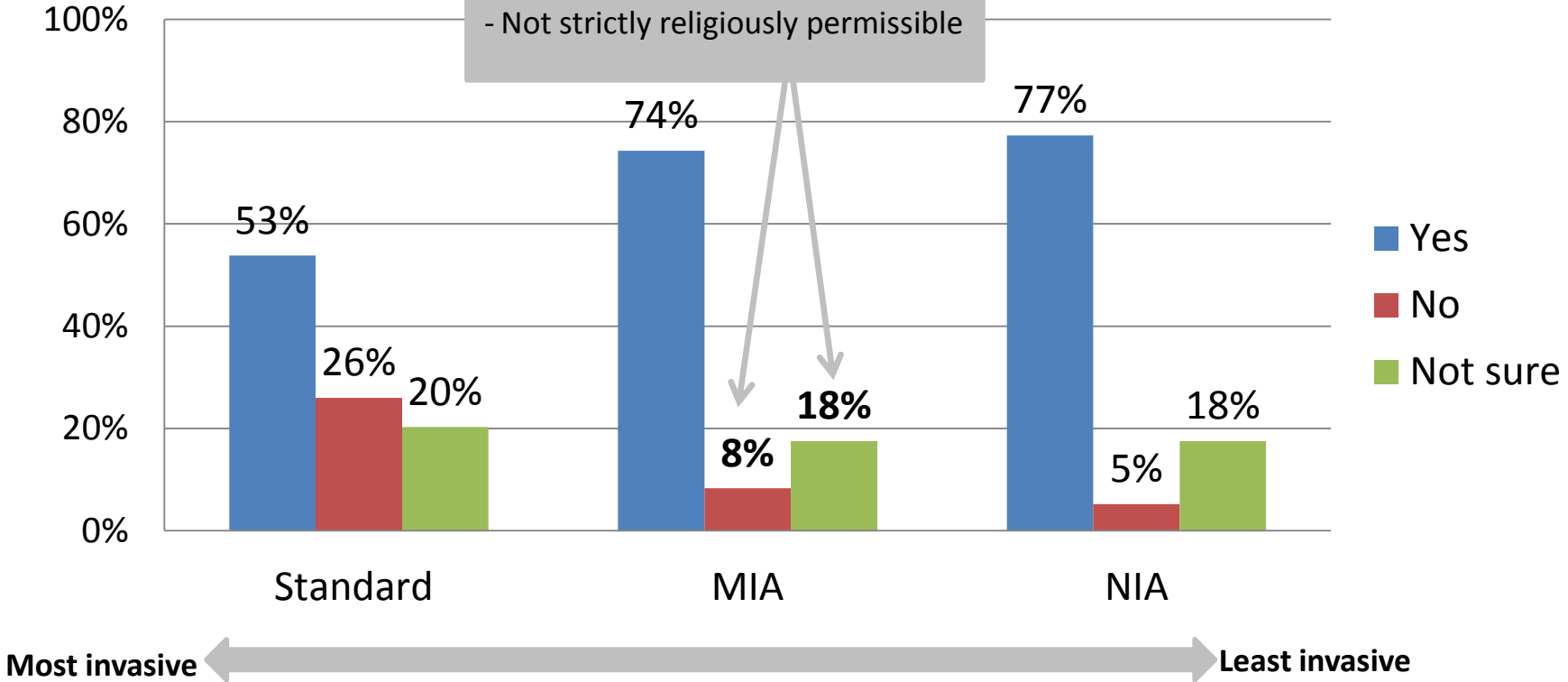
***“As it's new **would it find the answers parents need from an autopsy? If results came back inconclusive would parents then be left wondering if the answer was in a full autopsy?”*****

Sands, stillbirth, declined autopsy



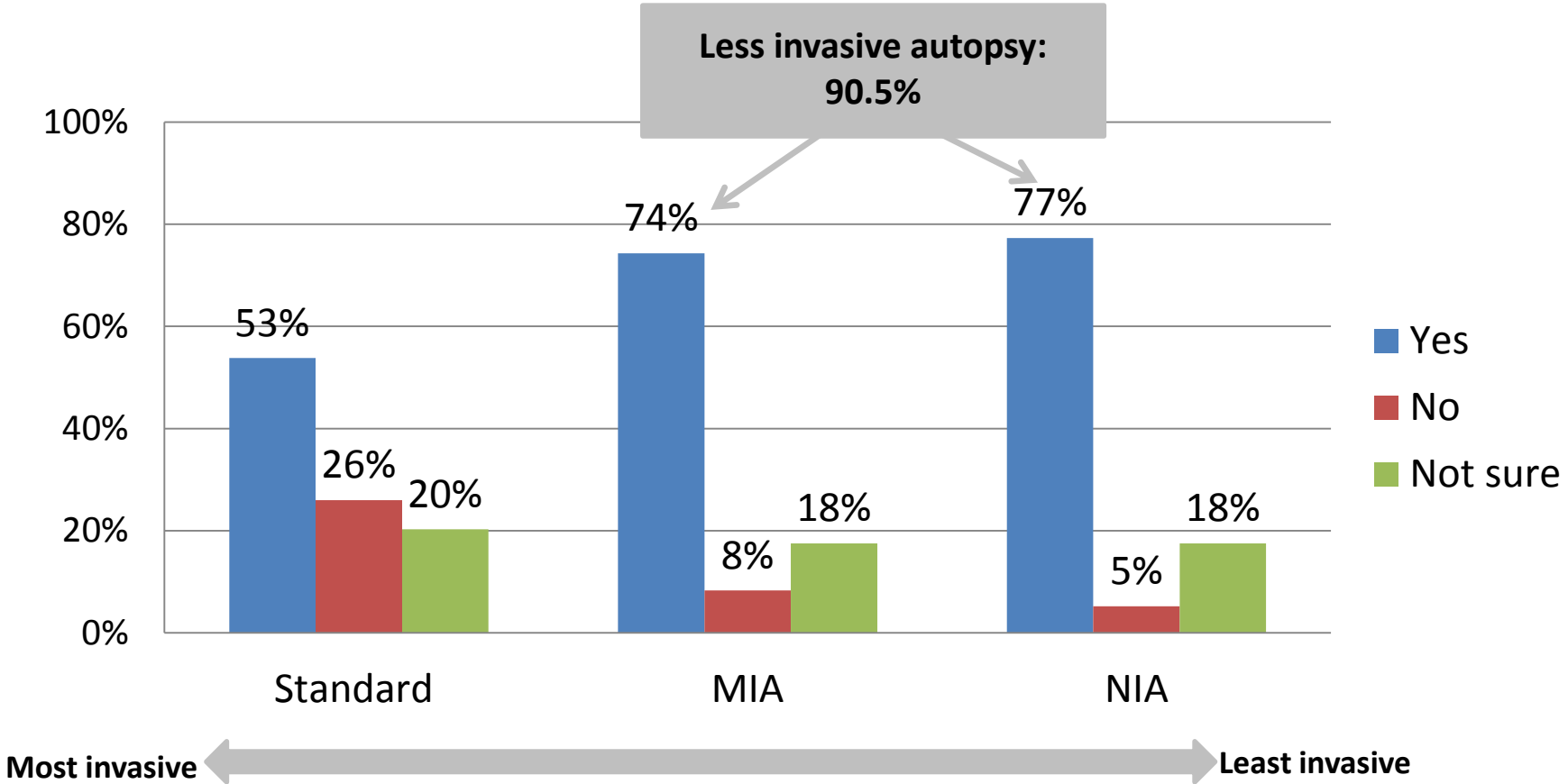
# Would you consent to the following types of PM?

**2. Still invasive**  
- Any incision is intolerable  
- Not strictly religiously permissible

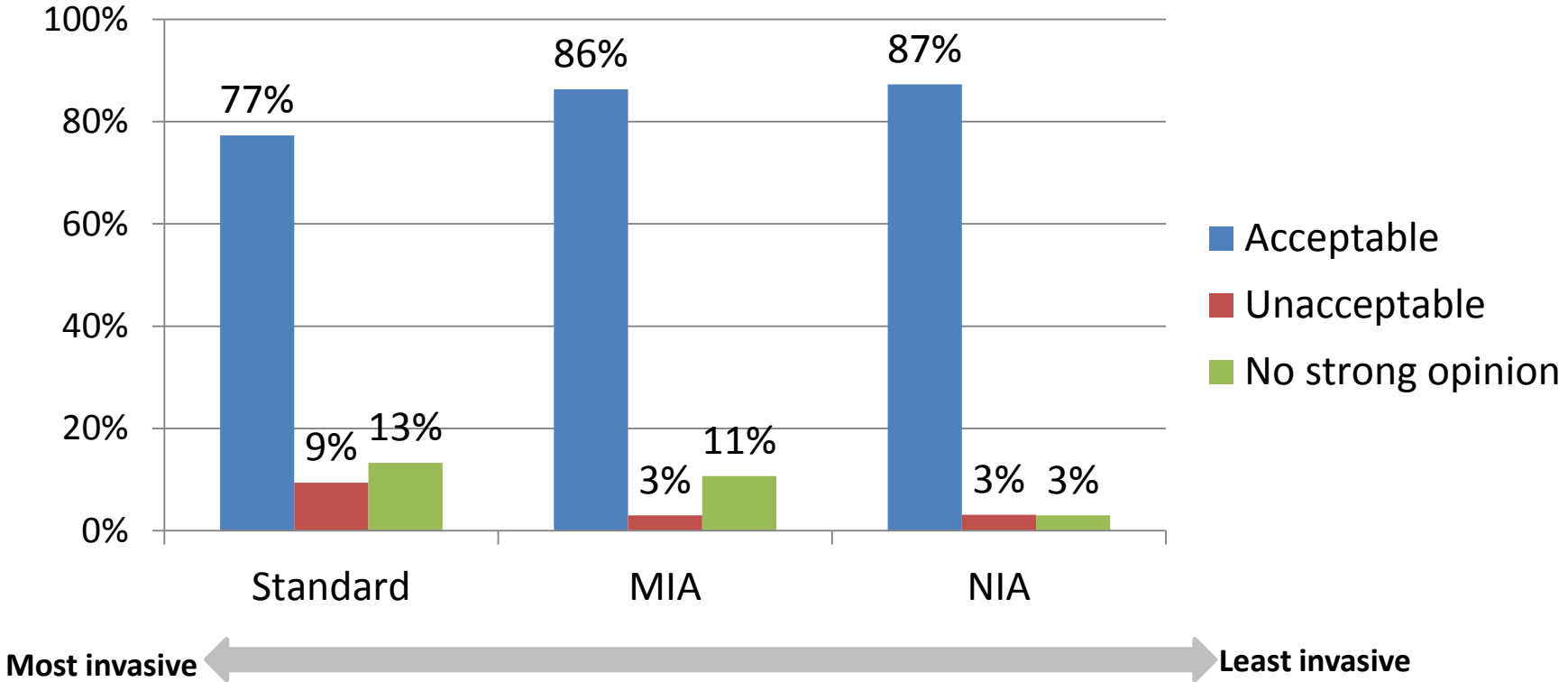


*“In the Islamic perspective, it’s **still forbidden** because of the cutting, whether it’s a big cut or a small cut.” (FG7, Mixed Ethnicity, Muslim, Women).*

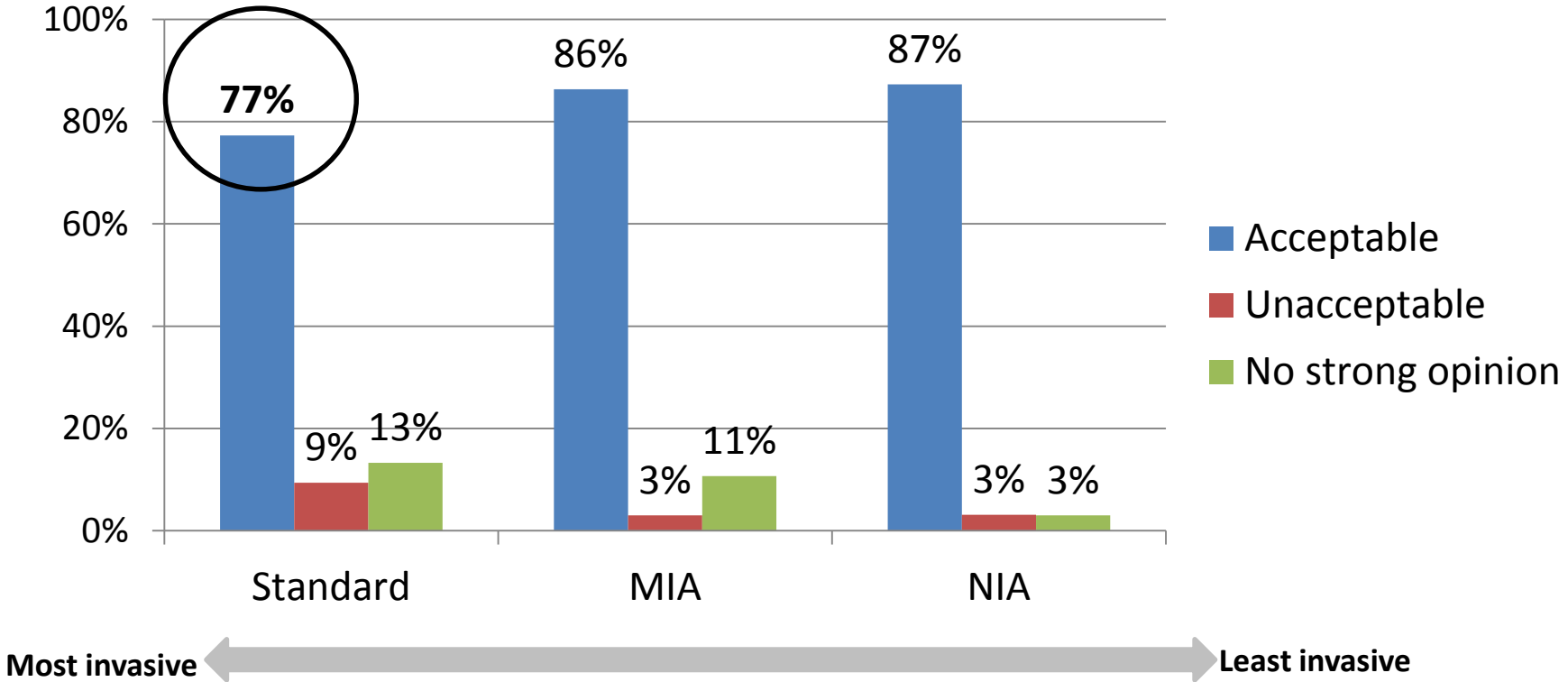
# Would you consent to the following types of PM?



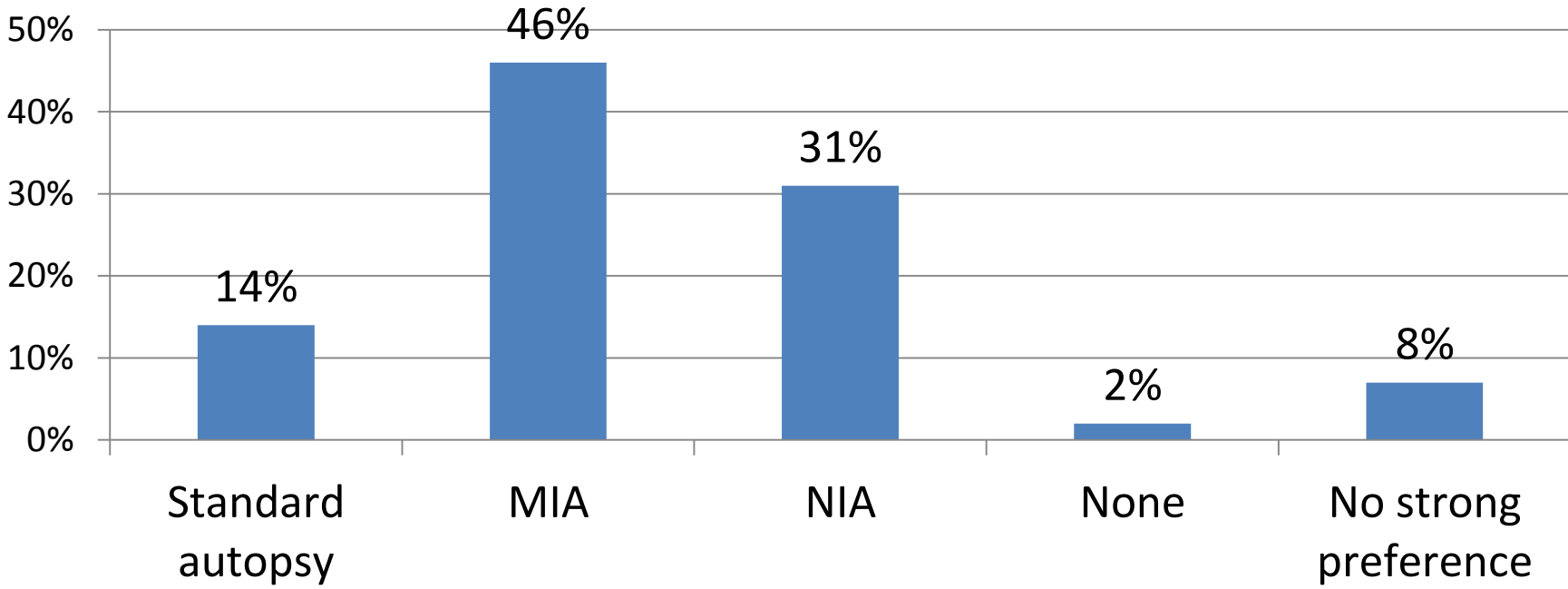
# How acceptable are the different types of PM?



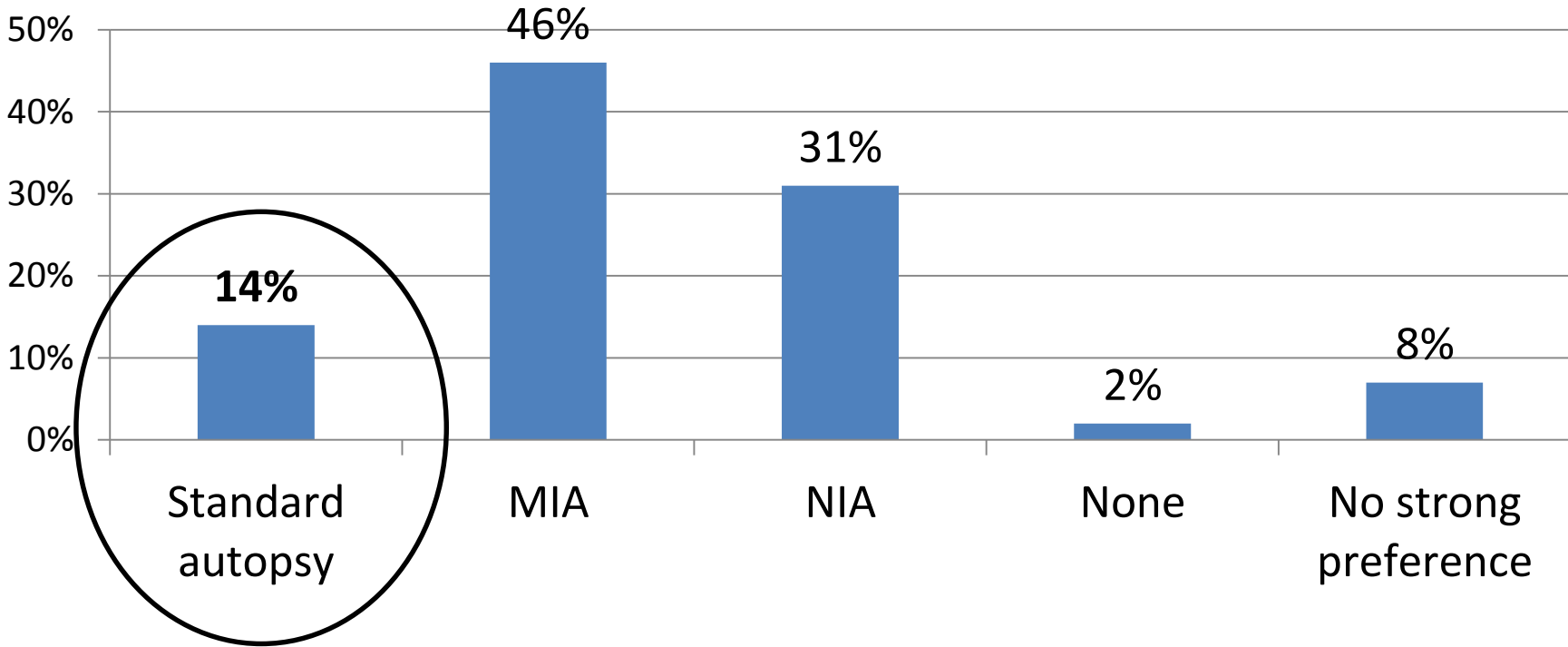
# How acceptable are the different types of PM?



# If you had the option, which would you choose?



# If you had the option, which would you choose?



# Summary

- Less invasive methods would open up **opportunities for people who would otherwise decline including religious groups**
- **Likely to be a significant increase in uptake** if personalised and more acceptable approaches were routinely available
- Some people will **still prefer standard autopsy** – important to offer choice
- Further work to **assess effectiveness of LIA in specific circumstances** to guide counselling
- Need for **economic/implementation evaluations**
- **REQUIRES SIGNIFICANT BUY-IN FROM HOSPITAL MANAGERS, PATHOLOGISTS & RADIOLOGISTS IN TERMS OF TRAINING, EQUIPMENT & WILL TO CHANGE**



# Publications

*Health professionals' and coroners' views on less invasive perinatal and paediatric autopsy: a qualitative study:* Lewis et al. 2018 **Arch Dis Child**

*“We might get a lot more families who will agree”: Muslim and Jewish perspectives on less invasive perinatal and paediatric autopsy.* Lewis et al. 2018 **Plos One**.

*Availability of Less Invasive Perinatal and Paediatric Autopsy will Improve Uptake Rates; A Mixed Methods Study with Bereaved Parents.* Lewis et al. 2019 **BJOG**

*“The communication and support from the health professional is incredibly important”: Processes and practices that support parental decision-making about postmortem examination.* Lewis et al. **Under review**

# Acknowledgements

## **Great Ormond Street Hospital**

Neil Sebire(PI)

Meg Riddington

Melissa Hill

Owen Arthurs

John Hutchinson

Lyn Chitty

## Participating Sites

**Basildon & Thurrock NHS  
Foundation Trust**

**Southend Hospital NHS Foundation  
Trust**

**Homerton University Hospital**

**The University Hospitals of  
Leicester NHS Trust**

**Newham University Hospital**

**University College London Hospital  
NHS Foundation Trust**

## Participating Support Groups

**Antenatal Results and Choices**

**Sands – Stillbirth and neonatal death  
charity**

**The Lullaby Trust**

**Child Bereavement UK**

This work was supported by a National Institute for Health Research (NIHR) Health Technology Assessment, grant number 14/168/02 and was supported by the NIHR Great Ormond Street Hospital Biomedical Research Centre. The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.