Women who decline HIV testing in pregnancy: the results of a national survey and the clinical challenges of managing their babies

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Clinical Case 1

- 5 y/o under paediatric follow up for unrelated chronic illness
- 3 admissions with pneumonia
- HIV test- positive
- Generalised lymphadenopathy + oral candidiasis
- WHO Stage 3 Disease
- CD4 20 (2%), Viral Load 230,000 copies
- Mother had declined testing for HIV in pregnancy (other testing accepted). Test was not re-offered

Clinical Case 2

- A child was born to a mother who had refused HIV testing in pregnancy (from Congo)
- Test had been re-offered by specialist midwife in pregnancy
- The mother did not speak English, the father refused to allow discussion with the mother alone or to allow a translator to be present.
- Seen by specialist midwife and paediatricians- Testing refused
- Discussion with tertiary unit- in the best interests of the child to know if HIV exposed
- Parents told the case would be referred to social care and may go to court for a judge to decide.
- At this point, the parents reluctantly agreed to testing
Clinical Case 3

- Testing refused in pregnancy (MDT involvement) - Mother from Botswana, father English - refusal to speak to Mum alone
- Did not believe data, felt victimised
- Moved to 3 hospitals, MDT involvement in each
- Continued refusal of testing for mother or baby
- Legal and MDT meetings
- No grounds for pursuing further
- GP informed

Background

**Antenatal screening programme for HIV**

IDPS Programme Standards were revised in 2010 and fully implemented by April 2012:

- Declines should be recorded and reasons for decline ascertained
- Formal re-offer of HIV screening for women who decline the initial offer, by 28 weeks gestation
- Formal re-offer may include discussion with screening coordinator
- Published alongside lab handbook which covered the standards of the testing and reporting process
- Service specification for commissioning antenatal ID screening
- Similar standards were also adopted by NHS Scotland, Public Health Wales, and IDPS NI
Background

Infected children born to women who declined antenatal HIV testing since 2006

- 28/67 children born to undiagnosed mothers
- Year of birth ranged 2006 to 2010, majority born 2006 to 2007
- Reasons for declining included: needle-phobia, did not feel she was at risk of HIV+, confidentiality concerns, being scared of positive result
- Evidence in 6 cases that woman was re-offered a test
- In 2 cases it transpired that women were concealing a previous positive diagnosis

Aims

To survey maternity unit practice in the UK to find out:

1. The number of women who delivered at the unit and declined HIV testing in 2014
2. Whether they had a local policy for women who decline antenatal HIV testing
3. What this policy involved, including whether they offered testing for the infants of women who declined testing
4. How they resolved cases where women declined antenatal HIV testing
Methods

- Collaboration between NSHPC & CHIVA
- Web-based survey (RedCap)
- Sent to all NSHPC respondents and CHIVA members by email
- Survey sent out in January 2015

Results

How many units responded?
- 43% response rate (91/214 units contacted)
  - 45% in England (76/169)

Who responded?
- Antenatal screening coordinator 40%
- Doctor (Paeds, O&G, GUM) 27%
- Specialist midwife 25%
- Other (midwife, CNS, GU nurse) 8%

Maternity unit size
- Median no. deliveries 5000/year
- Range 250 to 10,500
Results

Does your unit record the number of women who decline antenatal HIV testing?

- Yes 74%
- No 10%
- I don’t know 16%

I don’t know: 60% in paeds/GU vs. 2% midwives (p<0.001)

If yes – 53% record on electronic mat system, 17% on electronic lab system, 30% manually.

Decline rate 2014 (available in 50/67 units who record)

<table>
<thead>
<tr>
<th>No. of units</th>
<th>0 - 0.1%</th>
<th>0.1 - 0.5%</th>
<th>0.5 - 1%</th>
<th>1 - 1.5%</th>
<th>1.5 - 4%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Units</td>
<td>35</td>
<td>18</td>
<td>9</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Results

Does your unit have a local policy on the management of women who decline antenatal HIV testing?

- Yes 80%
- No 11%
- I don’t know 9%

No assoc. with size of unit or region

Paediatricians most likely to say I don’t know (p=0.005)

Who re-offers the test? (overlap)

- Community / non-spec midwife 71%
- Screening coordinator 26%
- Spec midwife 19%
- Obs / GUM cons 19%
- Other 4%

What if she declines the re-offer? (overlap)

- Not pursued further 41%
- MDT 27%
- Midwifery input 15%
- Other 23%
Results

Is the reason women give for declining recorded at your unit?

**YES** 43%  
**NO** 44%  
**I DON'T KNOW** 12%

If yes, where is it recorded? (overlap)

- Handheld notes 72%
- Hospital notes 36%
- EPR 36%
- Other 8%

<table>
<thead>
<tr>
<th>Reason for declining</th>
<th>Unit records reasons (n=39)</th>
<th>Reasons not recorded – respondent opinion (n=51)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at risk of HIV</td>
<td>56%</td>
<td>73%</td>
</tr>
<tr>
<td>Needle-phobia</td>
<td>54%</td>
<td>49%</td>
</tr>
<tr>
<td>Has had a prior negative test</td>
<td>41%</td>
<td>49%</td>
</tr>
<tr>
<td>Doesn't want to know HIV status</td>
<td>13%</td>
<td>29%</td>
</tr>
<tr>
<td>Is worried about confidentiality</td>
<td>0%</td>
<td>12%</td>
</tr>
<tr>
<td>No reason given</td>
<td>26%</td>
<td>24%</td>
</tr>
<tr>
<td>Other (e.g. declines all screening)</td>
<td>10%</td>
<td>10%</td>
</tr>
</tbody>
</table>

Results

Does your unit have a policy for women who attend in labour without a documented HIV test result?

**YES** 84%  
**NO** 10%  
**I DON'T KNOW** 6%

If yes, what is the policy?

- Offered a test immediately 92%
- Offered a test before she leaves hospital 1%
- Not routinely offered a test 3%
- Other 4%

What test would you use?

- Urgent lab HIV test 75%
- POC test on delivery suite 23%
- Routine lab HIV test 4%
- I don't know 8%

How quickly can you get the result?

- Within 2h 36%  
- Within 4h 18%  
- Within 8h 6%  
- Within 24h 24%  
- Within 48h 1%  
- I don’t know 15%
Results

Does your unit have a policy for testing the infant of a woman who has declined antenatal HIV testing?

**YES 21%**

**NO 68%**

**I DON’T KNOW 11%**

<table>
<thead>
<tr>
<th>What do you do? (note overlap)</th>
<th>Has policy (n=19)</th>
<th>No policy (or don’t know) (n=71)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Actively recommend infant testing (inpatient)</td>
<td>68%</td>
<td>13%</td>
</tr>
<tr>
<td>Actively recommend infant testing (community)</td>
<td>91%</td>
<td>1%</td>
</tr>
<tr>
<td>Recommend infant testing depending on risk assessment</td>
<td>58%</td>
<td>28%</td>
</tr>
<tr>
<td>Inform mother’s GP that she declined testing</td>
<td>16%</td>
<td>19%</td>
</tr>
<tr>
<td>No offer of testing for infant</td>
<td>0%</td>
<td>39%</td>
</tr>
<tr>
<td>Other</td>
<td>0%</td>
<td>5%</td>
</tr>
<tr>
<td>I don’t know</td>
<td>5%</td>
<td>11%</td>
</tr>
</tbody>
</table>

Results

What factors do you consider in your risk assessment?

<table>
<thead>
<tr>
<th>Risk assessment factors (note overlap)</th>
<th>Has policy (n=11)</th>
<th>No policy (n=21)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mother born in high prevalence country</td>
<td>91%</td>
<td>90%</td>
</tr>
<tr>
<td>Partner born in high prevalence country</td>
<td>73%</td>
<td>70%</td>
</tr>
<tr>
<td>Mother’s ethnicity if UK-born</td>
<td>36%</td>
<td>35%</td>
</tr>
<tr>
<td>Partner’s ethnicity if UK-born</td>
<td>36%</td>
<td>35%</td>
</tr>
<tr>
<td>Maternal history IDU</td>
<td>91%</td>
<td>90%</td>
</tr>
<tr>
<td>Partner history IDU</td>
<td>82%</td>
<td>75%</td>
</tr>
<tr>
<td>Maternal sexual history</td>
<td>91%</td>
<td>80%</td>
</tr>
<tr>
<td>Other</td>
<td>9%</td>
<td>0%</td>
</tr>
</tbody>
</table>
Results

What would happen if the parents declined the offer of infant HIV testing?

<table>
<thead>
<tr>
<th>Action (note overlap)</th>
<th>Has policy (n=18)</th>
</tr>
</thead>
<tbody>
<tr>
<td>We would discuss the case in a local MDT</td>
<td>67%</td>
</tr>
<tr>
<td>We would discuss with paediatric HIV centre</td>
<td>56%</td>
</tr>
<tr>
<td>We would inform infant’s GP</td>
<td>28%</td>
</tr>
<tr>
<td>We would discuss with CPT or similar</td>
<td>61%</td>
</tr>
<tr>
<td>We would consider going to court</td>
<td>44%</td>
</tr>
<tr>
<td>We would not pursue this any further</td>
<td>11%</td>
</tr>
<tr>
<td>Other</td>
<td>6%</td>
</tr>
</tbody>
</table>

Results

What would make you consider taking it further?

<table>
<thead>
<tr>
<th>Risk assessment factors (not all shown)</th>
<th>Has policy (n=18)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mother born in high prevalence country</td>
<td>89%</td>
</tr>
<tr>
<td>Mother’s ethnicity if UK-born</td>
<td>33%</td>
</tr>
<tr>
<td>Maternal history IDU</td>
<td>68%</td>
</tr>
<tr>
<td>Maternal sexual history</td>
<td>53%</td>
</tr>
<tr>
<td>None of the above</td>
<td>6%</td>
</tr>
</tbody>
</table>

Do you have access to a legal team who are able to offer advice in this situation?

YES 64%  NO 9%  I DON’T KNOW 27%
Results

How did you resolve cases where a woman declined all antenatal HIV testing at your unit in 2014?

<table>
<thead>
<tr>
<th>Action (note overlap)</th>
<th>Units (with at least one case, n=48)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No further action was taken</td>
<td>50%</td>
</tr>
<tr>
<td>Parents did not consent to infant testing despite MDT intervention</td>
<td>6%</td>
</tr>
<tr>
<td>Parents consented to infant testing after MDT discussion</td>
<td>13%</td>
</tr>
<tr>
<td>Parents consented to infant testing after notification of CPT involvement</td>
<td>6%</td>
</tr>
<tr>
<td>Court order enabled testing</td>
<td>0%</td>
</tr>
<tr>
<td>Other</td>
<td>8%</td>
</tr>
</tbody>
</table>

Conclusions

- Most units reported very low decline rates <0.5% but some >1%
- Most units that responded have a policy on women who decline retests offered by non specialist midwives
- Few units 21% have a policy of whether to offer testing for the baby
- Wide variation in practice, even where policy in place
- Reasons for declining thought broadly similar between units that record and those that don’t – most should be able to be dealt with by a sensitive discussion with an experienced clinician
- Needle-phobia seems to be a prominent reason for declining screening – all units should have a robust policy to manage this
Conclusions

• Offering testing for all infants of women who decline seems reasonable
• Subsequent management needs to balance the autonomy of the mother with the best interests of the child
• A need for guidance for paediatricians about infant testing when the woman has declined antenatal HIV testing and how to manage when infant testing is refused

Paediatric perspective

• Paediatricians need to act in best interest of the child
• Best interest of child is to not have HIV infection
• Knowing if a baby has been exposed to HIV allows interventions to prevent HIV infection and treatment of an HIV positive mother
• Screening in pregnancy not compulsory for blood borne infections
• Parents can refuse screening for other diseases (guthrie testing)
• Risk based assessment can be controversial
• Child protection and legal advice may be needed
Acknowledgments

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NSHPC Current team
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Administrative assistant: Icina Shakes
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Questions?
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