Women who decline HIV testing in pregnancy: a survey of local policy & practice

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Background

**Maternity services**

In 2013/14 there were approx **760,000 births** in the UK:

- England 650,000
- Scotland 55,000
- Wales 30,000
- N. Ireland 25,000

In England, maternity services are currently commissioned by 211 CCGs from NHS Trusts and Foundation Trusts, including antenatal screening services.
Background

Antenatal screening programme for HIV

Antenatal HIV screening is one of the most successful universal screening programmes in the UK.

- The DoH first recommended antenatal screening for HIV in areas of high prevalence in the UK in 1994, and the normalisation of HIV testing for all pregnant women was recommended in 1999.
- It is now part of the UK National Screening Committee’s Infectious Diseases in Pregnancy Screening programme, which currently sits in PHE.
- By 2012, the estimated uptake of screening had risen to 98% of women presenting for antenatal care in England.
- Latest data from 2013 estimates uptake 97-98% in England
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

Pregnancies in women diagnosed with HIV

Timing of diagnosis & ART at conception
UK & Ireland 1998-2014

* All pregnancies reported by December 2014, regardless of outcome; reporting delay for recent years
** Other category is pregnancies lacking information on precise timing of diagnosis and/or ART use
Background

Children diagnosed with perinatal HIV born in the UK since 2006

- Woman diagnosed during pregnancy or at delivery
- Woman diagnosed before pregnancy
- Woman diagnosed after pregnancy / undiagnosed
Background

Age at diagnosis and year of birth of children with perinatal HIV born to undiagnosed women
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)
  → 43% in Scotland, Wales, Rep. Ireland & N.I. (15/45)

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)
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?**

<table>
<thead>
<tr>
<th>YES 43%</th>
<th>NO 44%</th>
<th>I DON’T KNOW 12%</th>
</tr>
</thead>
</table>

**If yes, where is it recorded? (overlap)**

<table>
<thead>
<tr>
<th>Handheld notes 72%</th>
<th>Hospital notes 36%</th>
<th>EPR 36%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other 8%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<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?

<table>
<thead>
<tr>
<th>YES</th>
<th>NO</th>
<th>I DON’T KNOW</th>
</tr>
</thead>
<tbody>
<tr>
<td>84%</td>
<td>10%</td>
<td>6%</td>
</tr>
</tbody>
</table>

**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>11%</td>
<td>1%</td>
</tr>
<tr>
<td>Recommend infant testing depending on risk assessment</td>
<td><strong>58%</strong> (red)</td>
<td><strong>28%</strong> (red)</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</td>
<td>6%</td>
</tr>
<tr>
<td>intervention</td>
<td></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</td>
<td>6%</td>
</tr>
<tr>
<td>involvement</td>
<td></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, but few have a policy of whether to offer testing for the baby
• Wide variation in practice, even where policy in place
• Reasons for declining 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 the infants of women who decline seems reasonable
• Decisions about subsequent management need to balance the autonomy of the mother with the best interests of the child
• It would be useful to have national guidance for paediatricians on the offer of infant testing to women who have declined antenatal HIV testing
Acknowledgments

NSHPC Ethics
MREC/04/2/009

NSHPC Current funding
Public Health England
The National Screening Committee

Additional funding
LB currently holds MRC Clinical Research Training Fellowship

NSHPC Current team
Principal investigator: Pat Tookey
Data manager & statistician: Helen Peters
Researchers: Kate Francis, Rebecca Sconza, Laura Byrne
Administrative assistant: Icina Shakes
Additional support: Claire Thorne, Catherine Peckham, Mario Cortina-Borja

Acknowledgements
Thank you to all the clinicians that responded to the survey!

Questions?
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