Don’t Forget the Children

Why are we here?

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Royal Society of Medicine
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Why are we here?

• Death of a child
• Undiagnosed HIV positive child
• Both parents in adult HIV care
• Could it have been avoided - Probably Yes
• Was it a freak situation? – We do not know – not enough data – but widespread concern that it could easily have happened elsewhere
• How to stop it happening again?
Why are we here?

• Recognised that this is potentially a widespread problem
• Lots of interest in the issue but a lot of uncertainty as to how to proceed
• A multi-sector problem
• Generous support from the Department of Health, The Elton John AIDS Foundation, Abbott, BMS, Pfizer, Tibotec, BHIVA, CHIVA and last but not least – Mediscript!

Why are we here?

This meeting has been set up to:
• Share knowledge and expertise
• Gather experiences and a variety of viewpoints
• Look at practicalities and protocols
• Facilitate multi-sector cooperation and working
• Develop models of best practice
• Produce materials to share this information more widely
• Agree on a strategy to take it forward
Don’t Forget the Children
What next?

Taking it forward

Dr Chris Wood

Principles - 1

• The health of the child is paramount
• The integrity of the child’s family is also paramount – unless the child safety is seriously threatened
• Possible undiagnosed HIV infection is a serious threat to a child’s safety
• It is also in the interests of the child to protect the integrity of the child’s family whenever possible
• Legal action against the family is a last resort
Principles - 2

• The number of undiagnosed HIV +ve children in the UK is unknown
• Children of any age at risk of undiagnosed HIV infection are at risk of potentially avoidable morbidity and mortality
• HIV is passed on through the mother not the father
• If the mother is proven to be HIV-ve throughout pregnancy and breastfeeding, including the ‘window period’, the child does not need to be tested
• One group of children at risk of undiagnosed HIV infection, can, be readily identified and tested.

Principles - 3

• HIV testing of children may be seen as a process – the urgency of the process depends on the age and health of the child
• 6 months may be a reasonable upper limit to that process
• Most cases are likely to be straightforward with parents keen to protect their child’s health
• Cases where parents are reluctant or refuse may need intensive support and/or intervention from a multi-disciplinary team
Practice - 1

- Standard of care required for HIV services – the HIV status of all the children of the HIV+ve Adults attending that service, should be known.
- It is recognised that many HIV services will have a backlog, with possibly hundreds or even thousands of untested children requiring HIV testing – how long is acceptable for this ‘look back’ process?
- It is a necessary, but time-consuming and resource intensive process, – some parents/families may need intensive support

Practice - 2

- Protocols should be in place to address the backlog of testing and the prospective gathering of data for new patients
- Protocols will depend on the local setting
- A multi-disciplinary team/network should be established with a clearly identified ‘parent pathway’ and ‘child pathway’
Practice - 3
The multi-disciplinary team/network should have regular meetings and be made up of identified individuals including:
• An adult HIV physician and a senior nurse/health advisor +/- specialist HIV midwife
• Identified paediatric consultant with responsibility for HIV and a senior paediatric nurse
• Identified Voluntary Sector and peer support where possible
• The Trust child protection/safeguarding team
• Social services and Council child

Protocols - 1
• Need an appropriate database to record basic data
• Need to be able to pro-actively manage cohort of possible parents (remember gay & bisexual men and women may have children too)
• Need to be able to proactively manage ongoing cases with a view of the ‘ticking clock’
• Clear thresholds to escalate referrals to next level of responsibility when necessary– ultimate local responsibility rests with Council Child Safeguarding Boards/Safeguarding Boards
Protocols - 2

Parent pathways need to be clearly established:

- Different cases will need different types of intervention – all need proactive management
- Straightforward – immediate testing of children, or mutually agreed deferral for set period
- Complex – more intensive involvement and family support required
- Absolute parental refusal and potential child safety case – identify early on for intensive multi-disciplinary support and early involvement of the multi-disciplinary team
Goals of Today

• Produce a consensus strategy to address the issue
• Raise awareness across sectors
• Practical help – databases, protocols, referral pathways
• Educational materials & strategy
• Standards document of recommendations for BHIVA/CHIVA/BASHH/BIS + other organisations