Policy Briefing: Access to formula milk for mothers living with HIV in the UK

Introduction

Breastfeeding is an identified route of vertical transmission (VT) of HIV.[1] The World Health Organisation (WHO) calculated that breastfeeding has been responsible for between 30%-60% of all HIV infections in children globally.[2] If an infant born to a mother living with HIV is fed exclusively with formula milk, as UK clinical guidance currently recommends,[3] there is no risk of post-natal transmission. In the UK, VT rates of HIV are at an all-time low of below 0.27%.[4] However, between 2006 and 2013 there were a number of new infant HIV acquisitions attributed to breastfeeding.[5] Despite this, the provision of formula milk currently lies outside of routine NHS provision.

The cost of formula milk can make it difficult to access for some mothers living with HIV. This is forcing some women to go hungry in order to afford formula for their infant – compromising their own health and potentially compromising the effectiveness of their HIV treatment.[6] Mothers with irregular immigration status and no recourse to public funds (NRPF)[7] and mothers with low income are particularly vulnerable to these barriers.

This briefing assesses the access that mothers living with HIV in the UK have to infant formula milk and makes a series of recommendations to ensure that this essential prevention tool is made available. Whilst this briefing only focuses on difficulties accessing formula milk as a barrier to formula feeding, it should be acknowledged that there are also significant personal, cultural, social and emotional barriers experienced by some mothers living with HIV in relation to formula feeding.[8] Alongside this briefing, due consideration should be given to the need for emotional and other forms of support to assist mothers living with HIV to formula feed.

We are aware that UK clinical guidelines are currently under review and that the global trend is towards breastfeeding in cases where the mother is virally suppressed due to effective antiretroviral treatment (ART). Nevertheless, there will always be some who do not achieve or maintain viral suppression for the time-period required, and for whom the risk of transmission requires access to formula feed. Prompt action is needed to ensure this access is in place for those who need it, even in advance of any update to clinical practice.

[1] VT is also known as mother-to-child transmission (MTCT), but we have avoided this wording as a result of concerns that it assigns blame to mothers, constructing them as "vectors of infection". HIV activists advocate the use of more neutral language that focuses on the event (Dilmitis, et al. 2012).
[2] World Health Organization. Guidelines on HIV and Infant Feeding 2010: Principles and recommendations for infant feeding in the context of HIV and a summary of evidence. WHO, Geneva, 2010. Available at www.who.int/child_adolescent_health/documents/9789241599535/en/index.html.
[3] British HIV Association (BHIVA) and Children's HIV Association (CHIVA) Position Statement on Infant Feeding in the UK. BHIVA/CHIVA Writing Group on Infant Feeding in the UK, 2010. Available at http://www.bhiva.org/documents/Publications/InfantFeeding10.pdf
[4] Peters, H. et. al., 2017. UK Mother-to-Child HIV Transmission Rates Continue to Decline: 2012–2014. Clin Infect Dis (2017) 64 (4): 527-528
[5] Byrne, L., 2015. NSHPC audit of perinatal HIV in children born in the UK. Presented at 2015 RCOG World AIDS Day event "Prevention of Perinatal HIV Infection: Aiming for zero transmission", London.
[6] Karpf, B., Spinks, R. & Smith, G, forthcoming 2017. Affording formula: HIV+ women's experiences of the financial strain of infant formula feeding in the UK. HIV Medicine.
[7] If a person has no recourse to public funds means they will not be able to claim most benefits, tax credits or housing assistance that are paid by the state.
[8] Tariq, S., et al., 2016. "It pains me because as a woman you have to breastfeed your baby": Decision-making about infant feeding among African women living with HIV in the UK. Sexually Transmitted Infections, 1, pp. 1-6. [Online] Available at: http://sti.bmj.com/content/early/2016/01/12/sextrans-2015-052224.full

1. Vertical Transmission in the UK

In the UK there are on average 1100 to 1300 live births to HIV positive women per year.[9] VT of HIV can occur before and during birth, or after birth via breastfeeding. Thanks to medical interventions VT rates in the UK are now as low as 0.27% since 2012. These interventions are:

- Managing the viral load of pregnant women through treatment, Antiretroviral Therapy (ART);[10]
- Managed vaginal delivery for women with an undetectable viral load at term;
- Caesarean section for women with a detectable viral load at term;
- Post Exposure Prophylaxis (PEP) for new-born babies;[11]
- Exclusive feeding with infant formula milk from birth.

The first four interventions are routinely provided through the NHS but this is not the case for the provision of formula milk, despite its ability to eliminate post-natal transmission risk. This is a fundamental omission which can undermine the other initiatives by medical professionals and parents to prevent VT and represents a commissioning gap in meeting UK clinical guidance.

1.1 Clinical Guidance on Infant Feeding and HIV

BHIVA (British HIV Association): Guidance for the management of HIV in pregnant women 2012 (including 2014 interim review); Position Statement on Infant Feeding 2010

To date, BHIVA has consistently recommended that in the UK, "all mothers known to be HIV positive, regardless of antiretroviral therapy, and infant PEP, should be advised to exclusively formula feed from birth." Breastfeeding is not recommended. If a mother who is virally suppressed chooses to breastfeed against this advice, intensive monitoring is recommended, including viral load monitoring and infant HIV testing on a monthly basis.

In addition, BHIVA and CHIVA (Children's HIV Association) have published a joint position statement that states clearly that all mothers living with HIV should be supported to formula milk-feed their infants.[12] They propose that as part of a package of care to prevent vertical transmission, a free starter pack of formula milk and appropriate equipment (including a steriliser and bottles) should be provided. They also suggest that for mothers who are not eligible for Healthy Start, provision should be negotiated at a local level.

WHO (World Health Organisation) guidance

WHO guidance recommends that mothers living with HIV exclusively breastfeed.[13] This recommendation was set in 2010 in recognition that in low-income settings where access to formula milk and equipment and/or clean water is limited, formula feeding was potentially unsafe or could lead to malnutrition. In such a context exclusive breastfeeding when a woman is on treatment is safer than mixed-feeding, which carries the highest risk of transmission when the mother is not virally suppressed.

WHO guidance states that "exclusive feeding with infant formula milk should be recommended for women with HIV where it is affordable, feasible, acceptable, sustainable and safe."[14] For this reason, BHIVA chose not to update UK clinical guidelines in line with the WHO change.

[9] NSHPC (2016) Quarterly Data Update: October 2016. Available at http://www.ucl.ac.uk/nshpc/resources/quarterly-data-update
[10] The aim of HIV treatment is to reduce the amount of HIV in the body to a very low level, below the point most viral load tests can find HIV in a blood sample (usually below 50 'copies' of HIV in a millilitre of blood). This is called an undetectable viral load. While pregnant, decisions on care will sometimes be informed by viral load, and whether or not it is undetectable.
[11] For the best chance of preventing HIV, babies born to mothers living with HIV will take HIV treatment for a short period after he or she is born, usually for 4 weeks.
[12] BHIVA and CHIVA Position Statement on Infant Feeding in the UK, November 2010. Accessible via: http://www.bhiva.org/documents/Publications/InfantFeeding10.pdf
[13] WHO. Guidelines on HIV and infant feeding. 2010. Principles and recommendations for infant feeding in the context of HIV and a summary of evidence. Accessible via: http://apps.who.int/iris/bitstream/10665/44345/1/9789241599535_eng.pdf
[14] BHIVA Writing Group, British HIV Association guidelines for the management of HIV infection in pregnant women 2012 (2014 interim review) p.50. HIV Medicine (2014), 15 (Suppl. 4), 1-77. Accessed via: http://www.bhiva.org/documents/Guidelines/Pregnancy/2012/BHIVA-Pregnancy-guidelines-update-2014.pdf

Guidance to healthcare commissioners

BHIVA's Standards of Care are designed to ensure those commissioning and providing care deliver equitable and high-quality services to secure the best outcomes for people living with HIV in the UK. Standard 8 on reproductive health states:

"All mothers known to be HIV positive should have access to the full range of interventions which have been shown to reduce the risk of onward HIV transmission, including free infant formula milk for those who are unable to afford it."[15]

The Standards of Care have been endorsed by the HIV Clinical Reference Group, who advise NHS England on the provision of HIV services.

Despite the clarity of these standards, infant formula is not routinely commissioned across the UK.

1.2 Transmission through breastfeeding

The National Study of HIV in Pregnancy and Childhood (NSHPC) collects data on all diagnosed women in the UK who are pregnant and their children. The NSHPC conducted a national audit of the 108 children born in the UK between 2006 and 2013 who were reported to have acquired HIV from their mothers.[16] The audit explored the circumstances of transmission during pregnancy and the postnatal period for each of these cases.

Although many cases of transmission were multifactorial, the NSHPC identified eight children where it was likely that the main reason they became infected was through breastfeeding. The NSHPC found that that the women in these instances faced complex social problems, such as uncertain immigration status and housing difficulties. Although the reasons for these infants being breastfed are unknown, a lack of access to free formula may have contributed to this.

1.3 The need to provide free infant formula milk to all mothers living with HIV

Those who are diagnosed in pregnancy face particular challenges to adjusting to life with HIV and adhering to daily medication at a time of great change in their lives. There is also evidence that women from poorer socio-economic backgrounds are more likely to find it difficult to adhere to treatment.[17] The health system should do all it can to support women living with HIV to exclusively formula feed their infants, and in doing so should alleviate the financial burden attached to this key prevention initiative.

Whilst some women living with HIV are more likely to struggle to pay for formula milk, we believe free formula milk and feeding/sterilising equipment should be made available to all mothers living with HIV irrespective of income and immigration status. Providing free formula milk, and the appropriate equipment to use it, responds to a basic prevention support right that all mothers living with HIV have (in the same way that condoms are routinely provided free of charge even though many people will be able to afford them). And importantly, the provision of free formula milk to all mothers living with HIV has the potential to retain women in HIV care post-pregnancy.[18]

There is also a clear financial argument to be made in support of the provision of free formula milk and feeding equipment. Providing formula milk for up to a year for mothers living with HIV would be a low-cost intervention compared to the lifetime treatment cost for an infant should they contract HIV. The lifetime treatment cost

[15] BHIVA Standards of Care for People Living with HIV, 2013. P.47. Accessible via: http://www.bhiva.org/documents/Standards-of-care/BHIVAStandardsA4.pdf
[16] Byrne, L., 2015. NSHPC audit of perinatal HIV in children born in the UK. Presented at 2015 RCOG World AIDS Day event "Prevention of Perinatal HIV Infection: Aiming for zero transmission", London, UK
[17] Speakman A, Rodger A, Phillips AN, Gilson R, Johnson M, Fisher M, et al. (2013) The 'Antiretrovirals, Sexual Transmission Risk and Attitudes' (ASTRA) Study. Design, Methods and Participant Characteristics. PLoS ONE 8(10): e77230
[18] E Williams et al. The impact of financial support for replacement infant feeding on postpartum attendance and outcomes for women with HIV. BHIVA 2014. Poster abstract P139. HIV Medicine 15(Suppl 3): 60

is currently estimated to be £360,800[19], but this is based on someone contracting HIV at 30 and living until aged 72. The cost would be far greater for an infant acquiring HIV in the first few months of life (approximately £622,800).[20] In contrast, the average cost of providing formula milk and feeding equipment to an HIV positive mother for 12 months is approximately £417.59 - £475.46 (without accounting for administrative costs and potential discounts available through procurement).[21] If this was provided to 1300 mothers per year, the cost would likely still be lower than lifetime HIV treatment for one child.

Recommendation: All mothers living with HIV in the UK should have access to free infant formula milk and feeding equipment as a key prevention right.

Recommendation: We recommend BHIVA's guidance on infant feeding is strengthened by recommending that all mothers living with HIV have access to free infant formula milk.

Recommendation: BHIVA's clinical guidance on infant feeding, standards of care and the BHIVA and CHIVA position statement on infant feeding should be fully implemented across the UK.

2. Access to financial support for formula milk in the UK

In all but one health and care system in the UK (Northern Ireland) there is no national policy to provide for universal access to formula milk for HIV positive mothers who may need it. There are some Government schemes that may relieve the financial pressure of buying infant formula milk which help facilitate access for specific groups. These are asylum support for people with no recourse to public funds and the Healthy Start scheme for people with low income. However, evidence from HIV support organisations suggests that this support is insufficient. We also believe that there is a wider prevention right that all women living with HIV should be able to access free formula milk irrespective of income.

2.1 Healthy Start

Healthy Start is a UK-wide Government scheme to improve the health of low-income pregnant women and families with young children on benefits and tax credits. Healthy Start vouchers are free and provided every week to spend on milk, fruit and vegetables, infant formula milk and vitamins. To qualify for them a woman has to be at least ten weeks pregnant or have a child under four years old and the family receive one of the following:

- Income support
- Income-based jobseeker's allowance
- Income-related employment and support allowance
- Child tax credit (family income of £16,190 or less per year)
- Universal credit (family take-home pay of £408 or less per month).

Some people assume that the provision of healthy start vouchers is sufficient for mothers living with HIV on low income to buy formula milk. This is not the case. We have been notified by HIV service providers of several problems. Mothers do not always realise that they are entitled to access Healthy Start and even if entitled, some have experienced delays in accessing it. Even when they can access it, the vouchers are insufficient to cover the costs of infant formula milk in addition to other food that is urgently needed.[22] There is also an issue around stigma felt by mothers using Healthy Start as well as barriers experienced with cashiers, who may ask questions around the purchasing of formula milk.

[19] Nakagawa F et al. Projected Lifetime Healthcare Costs Associated with HIV Infection. PLOS One 10(4): e0125018, 2015.
[20] BHIVA. Saving Lives Saves Money: Preventing Mother-To-Child HIV Infection Saves NHS £3.1 Billion.; 2015. Available at: http://www.bhiva.org/saving-lives-saves-money.aspx. Accessed December 19, 2016.
[21] Based on Which? data estimating the cost of formula milk for 12 months as £367.59-£395.46, an electric steam steriliser as £40-£60 and six bottles as £10-£20. The Which? guide to baby feeding products is available here: http://www.which.co.uk/reviews/baby-feeding-products/article/buying-baby-feeding-products/baby-bottles-and-teats.
[22] The Healthy Start website states that families with babies under one year old get two vouchers each week (totalling £6.20) Accessed via: https://www.healthystart.nhs.uk/for-health-professionals/faqs/#3

Finally, Healthy Start only covers a proportion of women living with HIV who are in need of or would benefit from free formula milk; some will not qualify.

2.2 Asylum Support

People seeking asylum in the UK have no recourse to public funds, meaning they are not entitled to the same welfare provisions as those who are ordinarily resident here. Those with an open claim are provided with accommodation on a no choice basis and are given a basic support rate in cash-less form to cover their essential needs. Those whose appeals rights are exhausted lose this provision unless they are able to demonstrate they are taking reasonable steps to leave.

Current basic support payments work out to approximately £5 per day per person, and are not enough to support those living with HIV to meet their basic needs, let alone cover the cost of infant formula milk. Midwives have told us that in some cases mothers in this situation will not eat themselves to ensure their baby has formula milk, which can compromise their own health, especially if the treatment they are taking requires calorie intake for absorption. A recent survey by support organisation Body & Soul found that over 50% of the mothers who use their service had at times gone hungry in order to buy formula milk for their baby during the first twelve months of their infancy.[23] We believe women in these circumstances should not have to face this choice.

Body & Soul Case Study[24]

Nnenna* came to the UK from West Africa on a student visa and successfully gained a postgraduate degree. She then fell pregnant and was diagnosed as being HIV positive during routine blood tests. She was forced to leave her home and her abusive husband making her homeless and destitute. She currently lives in a shelter for victims of domestic violence with her baby Kado*.

Kado tested negative for HIV. Nnenna, was advised not to breastfeed her baby. However, she has found it extremely difficult to afford her baby's formula milk each week as well as her own food. Her only source of income is weekly social services payments under Section 17 of the Children's Act 1989 of £70; she does not have recourse to public funds and so is not eligible for benefits or Healthy Start vouchers. At £6.20 a week, Healthy Start vouchers would not cover Kado's requirements anyway. Her HIV clinic does not currently have a scheme for HIV positive mothers to receive formula milk.

It costs £17 a week – almost 25% of her total income - for Nnenna to buy 2 tubs of formula milk for Kado. She often has to go hungry in order to feed her baby and has no money left to buy winter clothes or other essentials. Nnenna was apprehensive about asking social services for more money, but after building up the courage to ask she was refused.

*All names have been changed.

Recommendation: Asylum support payments or Healthy Start payments should not be considered sufficient to meet the needs of mothers living with HIV who need support to access formula milk.

[23] Karpf, B., Spinks, R. & Smith, G, forthcoming 2017. Affording formula: HIV+ women's experiences of the financial strain of infant formula feeding in the UK. HIV Medicine.
[24] Case study provided by Body & Soul. Body & Soul is a pioneering UK charity dedicated to transforming the lives of children, teenagers and families living with, or affected by HIV.

3. Current access to free formula milk to mothers living with HIV across the UK

The lack of policy or agreed commissioning responsibility for provision of free formula milk has resulted in a patchwork of schemes and funding for formula milk that differs from area to area. This has led to a post-code lottery for those women who need to access it. In some areas the local authority or the NHS provides funding; in some areas access to schemes is restricted to certain groups of women living with HIV and in some areas there are no schemes or funding available at all.

In areas with a scheme, this has often been developed by individuals who have championed the needs of mothers living with HIV.

Recommendation: In areas that currently have an ad-hoc free formula milk scheme, funding should be protected until national provision is available.

As health is a devolved policy area, the sections below outline the situation in each of the home nations.

3.1 England

BHIVA guidelines on infant feeding are applicable in England, yet there is no comprehensive provision of formula milk for mothers living with HIV. Across England a number of free formula milk schemes exist. Historically these were commissioned by Primary Care Trusts, with some additional schemes provided through maternity units and community and voluntary sector organisations. Some of these schemes still exist today but they are not sufficient to meet the need we are aware of.

Example of an area in England with a formula milk scheme: Nottingham University Hospital

At Nottingham University Hospital (NUH) all new mothers living with HIV are counselled around the recommendation to formula feed their new baby. The Trust has recognised that within many cultural groups breastfeeding is the norm and women can receive unwanted attention if they take the option to bottle feed. The counselling provided therefore includes discussion around coping with social issues and concerns related to bottle feeding. NUH has an HIV specialist paediatric nurse who, along with community midwives, is then responsible for follow-up with women on their adherence to formula feeding at home.

Some mothers living with HIV and on low incomes can access free formula milk through NUH. Because the Trust is recognised as ‘Baby Friendly’, they cannot advertise any form of formula milk, be it on leaflet, pens, posters etc. and the funding for this free formula milk has to be from a hospital source external to that in maternity. Those who do qualify for the scheme are provided with formula milk for six months following the birth of their child. For families living in poverty NUH also has access to a range of local social enterprises that can provide bottle feeding equipment. However, women are expected to provide the formula milk themselves if their household is not entitled to financial benefits.

Previously free formula milk was distributed on a monthly basis at home by a social worker. However, due to cut-backs, women must now attend the hospital once a month to collect this supply, which is ordered to one of the postnatal wards and stored there in advance. This does mean that they can access a supply 24/7 should they accidentally run out, spill or contaminate the milk.

3.1.1 London

To better understand the extent of free formula milk provision we undertook a mapping exercise across London. All but one of London's local authorities have high HIV prevalence[25] and we wanted to see how provision met need across the city. To do this we conducted telephone interviews with HIV midwives and conducted a survey. Although the survey did not provide a comprehensive picture for each London borough, it did provide examples of existing schemes and notified us of areas without provision.

Overall there were 26 responses to the survey. Two responses related to an area outside of London. Key findings of the survey were as follows:

Areas with a scheme

- Where schemes exist they vary in terms of who can access them.
- There is no consistency between schemes in terms of who they provide formula milk to, how the formula milk is provided and how it is commissioned.
- Schemes have often only continued to exist through the determination of individuals who have championed them.
- Some schemes do not have a stable funding mechanism and at time of writing, one scheme is due to end.

Areas without a scheme

- There are a number of areas within London where respondents identified a definite need for a formula milk scheme, but a service wasn't currently being provided
- Where there isn't a scheme women are having to find ways to pay themselves
- There are instances where mothers will not eat properly themselves in order to ensure their baby has formula milk

Example of an area in London with a scheme: Guys and St Thomas' Hospital (GStT) / Lambeth, Southwark and Lewisham

Every HIV positive pregnant woman living in Lambeth, Southwark and Lewisham seen in the clinic at GStT receives a formula feeding starter kit which consists of: a steriliser, four bottles and four tins/boxes of formula milk (choice between two brands).

For those women who reside in Lambeth, Lewisham or Southwark and have no recourse to public funds, they continue to receive formula milk (four tins/boxes every month) until their baby is one year of age. This is funded through the Clinical Commissioning Group (CCG) and delivered through the Clinical Nurse Specialist team.

The approximately 30% of GStT pregnant patients living with HIV who reside outside Lambeth, Southwark and Lewisham receive nothing. For these mothers GStT used to use CWAC (Children with AIDS charity) formula milk grant scheme, but CWAC has now closed down. Some women may be able to access a THT Hardship Fund payment if they have not claimed this before, but this is usually only around £150, which would probably only cover a 'starter kit'.

[25] Public Health England defines local authorities as having a high prevalence of HIV if there is more than two people in every 1000 living with diagnosed HIV.

Example of an area in London without a scheme: HIV Midwife at a London hospital with no formula milk provision

Susan* is an HIV specialist midwife at a hospital in a high-prevalence area of diagnosed HIV in London where there is a large migrant community. There is no formula milk scheme provided by the NHS trust or the Local Authority. She says:

"As a midwife, having to tell mothers in this situation that they can't breast feed and not be able to support them is embarrassing. Some of these women are living a hand-to-mouth existence, living in churches and relying on hand-outs to survive. The cost of formula milk can be as much as £10 per pack and that is simply money that they don't have. If they have other children to support then this becomes financially impossible.

On average I reckon there are four to five women a month I come across who should be supported to have formula milk. I do refer some of my clients to a charity, which will see the women weekly. However, it is a small charity and I feel that I can't abuse their service. I therefore have to be selective with who I refer for help.

It is a public health issue that should not be ignored."

*All names have been changed

3.2 Northern Ireland

Until very recently, infant formula milk was not provided on the NHS in Northern Ireland and there was no provision of statutory funding for formula milk schemes. The only scheme providing free formula milk to mothers living with HIV with no recourse to public funds or those on low incomes was funded by a charitable trust fund - RVH 2Kare Trust[26], established by the Regional HIV Social Work Team, which generates income through fundraising and donations.

However, through successful lobbying of the NI Assembly, it was recently agreed that the Belfast Health & Social Care Trust would fund the provision of free formula milk on an ongoing basis. This will be coordinated by the regional HIV social work team, and will be available to all mothers living with HIV in Northern Ireland as part of a wider package of assistance for mothers to ensure they are as healthy as possible before and after birth. Mothers will be provided with a starter pack, including feeding and sterilising equipment along with formula, upon discharge from hospital, and thereafter collect formula when attending the hospital for reviews. Where necessary, volunteers or social workers on the team may deliver to their home.

3.3 Scotland

There is no Scotland-wide provision of free formula milk to all mothers living with HIV through the NHS. However, there are two schemes funded through two NHS Health Boards (NHS Greater Glasgow and Clyde and NHS Lothian) and provided by the voluntary sector.

Given the concentrated nature of the epidemic in Scotland (with higher prevalence in the Glasgow and Edinburgh areas) these schemes are likely to meet much of the demand for formula milk. Despite this, where possible we would continue to recommend that free formula milk is available to all mothers living with HIV in Scotland.

[26] RVH 2Kare Trust was established by the Regional HIV Team (NI) in the Royal Victoria Hospital, for the benefit of men, women, young people and children, living with HIV disease in Northern Ireland. The group offers small grants to help restore independence, self-worth and dignity. The funding for this project is raised by people in Northern Ireland, for people living in Northern Ireland with HIV

Example of a formula milk scheme in Scotland: Waverley Care African Health Project

"I was so worried about how I was going to buy enough milk for the baby as it is so expensive. Getting free milk has freed me to buy other healthy food for me and the family. I know I have enough milk for my baby and so I don't have to worry about this."

Waverley Care are funded by two health boards to deliver a formula milk scheme as part of their African Health Project. Despite the overarching project name, the scheme is not only for African women. It is open to women receiving Healthy Start, those with low income or those with no recourse to public funds, which is determined through a means testing process.

Mothers are provided with a starter pack of a steam steriliser, eight bottles and four tins of formula milk. Four further tins are then provided each month up until the child's first birthday. The scheme is run alongside a mother and baby group open to all women living with HIV from pregnancy until the child is two. Women are referred into the scheme and group via the HIV midwife. In 2014/15, the scheme provided 29 HIV positive mothers with free formula milk and parenting support and 822 tins of formula milk were distributed.

3.4 Wales

At the time of writing there is no national policy or scheme that ensures all mothers living with HIV in Wales have access to free infant formula milk.

Third sector organisations in Wales told us some mothers struggle to afford infant formula milk, most notably those without recourse to public funds, and that there are limited options of filling the funding gap for this group of women.

Midwives told us during the antenatal period they discuss methods of feeding with mothers and whilst an inpatient they normally supply formula milk to the mother, discharging them with about a week's supply to tide them over till they are able to purchase more. Formula milk is stored away as they promote the Baby Friendly Initiative.

Healthcare professionals working in the community who had experience with destitute asylum seekers with no recourse to public funds told us mothers are usually supported via the destitution clinic and an application for section 4 support is completed.[27] Whilst parents are in initial asylum accommodation in Cardiff they tend to get Tesco vouchers to go towards baby milk, but that is usually only for a few weeks.

Overall, it appears mothers living with HIV are only provided with formula milk whilst an in-patient at hospital. However, the provision of formula milk otherwise relies upon the assumption that women can afford it themselves, or that those who can't will have their needs met through the Healthy Start scheme or asylum support. For the reasons mentioned earlier in the briefing, this is not sufficient provision for women who will struggle to afford infant formula milk.

[27] No longer section 4 support post Immigration Act 2016

4. Impact of the Baby Friendly Initiative

Throughout this project NAT has come across instances where funding, commissioning and provision of formula milk to mothers living with HIV have been made difficult due to the Baby Friendly Initiative in hospitals.

"Due to our Trust being recognised as 'Baby Friendly' the funding for the formula milk is from a hospital source external to that in maternity. We do not advertise any form of formula milk, be it on leaflet, pens, posters etc."

"My manager doesn't 'get it' and suggested it [formula milk provision] should be within the remit of health workers, but they have all signed up to the baby friendly initiative. Formula milk can't be on display in the office, for example."

The Baby Friendly Initiative is a worldwide programme of the WHO and UNICEF. It was established in 1992 to encourage maternity hospitals to implement the Ten Steps to Successful Breastfeeding. Whilst we do not disagree with the aims and intentions of the initiative for HIV negative mothers, we have concerns that it has not taken due consideration of UK clinical guidance that mothers living with HIV should exclusively formula feed. Even if these guidelines were to change in future and breastfeeding were recommended in cases of viral suppression, there will always be a number of women who will be clinically recommended to exclusively formula feed.

The existence of the Baby Friendly Initiative should not hinder the ability of hospital staff to provide formula milk and advice to mothers living with HIV, nor should it hinder commissioning activity to support this.

Recommendation: Those responsible for implementing the Baby Friendly Initiative in the UK should give due consideration to UK clinical guidelines that mothers living with HIV exclusively formula feed their babies to prevent transmission. Explicit exemptions should be made so as not to restrict the commissioning and provision of free formula milk to mothers living with HIV.

5. Commissioning and provision of formula milk

5.1 Commissioning

We acknowledge that both NHS and Local Authority budgets are under a lot of pressure and that within this challenging environment difficult financial choices are having to be made. However, there are relatively low numbers of births to mothers living with HIV per year, and the cost of formula milk for up to a year is a fraction of the lifetime treatment costs that would be incurred should an infant otherwise become infected.

In line with our recommendation that all mothers living with HIV have access to free infant formula milk it needs to be commissioned in a way that guarantees universal access. To ensure this, the most appropriate body to commission formula milk provision to mothers living with HIV would be the NHS. NHS commissioning of formula milk in England, Scotland and Wales, in a similar manner to the approach adopted by Northern Ireland, would ensure it is accessible to all mothers living with HIV.

For England, we believe that universal access is best enabled through specialised commissioning for HIV as part of the provision of HIV. NHS England's Service Specification for HIV (Children) specifically includes pregnant

mothers living with HIV as a patient group under their care, and repeatedly refers to interventions required

to prevent vertical transmission. It also considers BHIVA guidelines and the BHIVA Standards of Care (both of which include recommendations on formula milk) as important documents of reference.

For Scotland and Wales, we believe that formula milk provision should be funded by the Health Boards to ensure universal access, emulating the approach adopted by Northern Ireland. Free provision of formula milk removes the cost barrier to formula feeding for mothers living with HIV, enabling access to a key prevention tool in eliminating vertical transmission.

In the meantime, commissioning bodies with more direct responsibility for public health or local population health (PHE, Local Authorities and CCGs) should look to strengthen guidance around commissioning and providing free infant formula milk for mothers living with HIV and do more to support existing schemes and initiatives. The National Maternity Review states that mothers should receive "personalised care… based around their needs and their decisions, where they have genuine choice"[28] and ensuring that formula milk is freely available means that mothers can make decisions on how to feed their infant without being influenced by cost.

Recommendation: NHS England should consider funding free formula milk for mothers living with HIV nationally through specialised commissioning as part of the prevention of vertical transmission.

Recommendation: Whilst commissioning at a national level is being considered, local authorities and CCGs (or equivalent) should fill the gap in provision in the meantime.

Recommendation: NHS Health Boards in Scotland and Wales should consider funding free formula milk for mothers living with HIV as a key prevention right.

Recommendation: In the event that future UK clinical guidelines recommend breastfeeding in the case of viral suppression, the NHS should continue to fund free formula milk where needed, based on clinical judgment (including but not limited to mothers with detectable viral loads, those finding adherence challenging and where fear of transmission causes psychological distress).

5.2 Provision

Based on our assessment of the need for formula milk provision in the UK and the schemes we have encountered, we believe formula milk should be provided to mothers living with HIV to cover the first year of an infant's life. Provision for a year will include the six months where the infant should be exclusively breastfed and also the weaning period. It is crucial that feeding/sterilising equipment is also provided so mothers are able to formula feed safely.

Consideration also needs to be given as to how formula milk could be provided to mothers living with HIV in a way that it is accessible, non-stigmatising and links women into care. Following an options appraisal, where we also considered the options of prescribing and provision via maternity or paediatrics, we have determined that the optimal way to meet these needs would be to provide formula milk and feeding/sterilising equipment via the HIV clinic.

Provision through the HIV clinic creates an opportunity to better retain some mothers in HIV care, who might

[28] NHS England (2016) National Maternity Review: Better Births – Improving outcomes of maternity services in England: A Five Year Forward View for maternity care.
[29] Tariq, S., Elford, J., Chau, C., French, C., Cortina-Borja, M., Brown, A., Delpech, V., Tookey, P. A. (2016). Loss to Follow-Up After Pregnancy Among Sub-Saharan Africa-Born Women Living With Human Immunodeficiency Virus in England, Wales and Northern Ireland: Results From a Large National Cohort. Sex Transm Dis, 43(5), 283-289.

otherwise be lost to follow-up after pregnancy. One study estimates that one in eight HIV positive women do not return for HIV care in the year after pregnancy,[29] the exact length of time we recommend they should be able to access free formula milk. Another study has demonstrated how a free formula milk scheme improved retention in care.[30]

In terms of accessibility and reducing stigma, clinics should consult with service users on how they would prefer formula milk and feeding/sterilising equipment to be provided, as well as taking into account local conditions. Possible delivery mechanisms could be direct provision at the clinic or provision via supermarket vouchers.

Vouchers allow greater choice of brands, increased accessibility for mothers who have greater distances to travel to their clinic, and removes the issue of storage for HIV clinics. Transportability of formula milk is also less of an issue as rather than having to collect a large number of tins at once from a clinic, mothers can shop more regularly for formula milk.

Example of a scheme that provides formula milk via vouchers: Jonathan Mann Clinic at Homerton Hospital

Jonathan Mann Clinic run a scheme which provides vouchers for pregnant women and new mothers living with HIV, enabling the purchase of sterilisers, bottles and formula milk. The scheme is available to women who deliver at Homerton or are residents of Hackney and attending HIV care at other clinics. At 30 weeks, expectant mothers gain an entitlement letter from their midwife which they take to their HIV department, helping with compliance with care and treatment. They are given an initial voucher of £120 in the form of a Tesco payment card, which is then followed up with a further £80 at their six-week post-natal appointment, and another £80 three months later. The scheme has been well received by mothers who report that it has removed much of the fear they had about not being able to breastfeed. The scheme is funded by the local authority and supports approximately 50 women per year.

Direct provision via the clinic is another option. A number of the case studies outlined in previous sections of this briefing showcased schemes that directly provide formula milk to mothers living with HIV, demonstrating that this can be an effective route of provision. Some mothers may prefer this method of provision and find vouchers stigmatising as they identify them as ‘different’ from other shoppers. Direct provision could also offer a more cost-effective option for HIV clinics given the discounts that effective procurement can achieve.

There may also be merits to providing formula milk through other settings such as the voluntary and community sector or any other suitable venue or delivery mechanism that best meets local conditions and patient needs; these can be arranged through agreements with HIV clinics if provision directly or via vouchers is not a workable option.

Recommendation: Formula milk should be provided to mothers living with HIV to cover the first year of an infant’s life.

Recommendation: Formula milk and feeding/sterilising equipment should be provided to mothers living with HIV via the HIV clinic. HIV clinics should determine the best route of provision through consultation with their service users and consideration of local conditions.

[30] E Williams, L Barnes, C Rowsell, M Islam, N Amofa, M Wills, J Anderson and T Barber (2014). The impact of financial support for replacement infant feeding on postpartum attendance and outcomes for women with HIV. HIV Medicine 15(60):60-60

6. Summary and Recommendations

Breastfeeding is an identified route of transmission of HIV and national guidelines advise exclusive formula feeding for infants, yet formula milk is the only vertical transmission prevention tool not routinely commissioned by the NHS. This has resulted in a postcode lottery for mothers living with HIV who need to access formula – particularly those who struggle to afford it. Our research for this briefing has revealed that financial support in the form of asylum support payments and Healthy Start vouchers, is inadequate or unavailable to mothers who are struggling to afford formula milk, and this has led to instances of mothers risking their own health by foregoing food for themselves.

Formula milk, and the appropriate equipment to use it, should be nationally available to mothers living with HIV as a key prevention right. Mothers living with HIV must be supported to make well-informed decisions and genuine choices in how they will feed their infant, and free provision of formula milk ensures that financial cost is not a factor in those decisions.

Recommendation: All mothers living with HIV in the UK should have access to free infant formula milk and feeding equipment as a key prevention right.

Recommendation: We recommend BHIVA's clinical guidance on infant feeding is strengthened by recommending that all mothers living with HIV have access to free infant formula milk.

Recommendation: BHIVA's clinical guidance on infant feeding, standards of care and the BHIVA and CHIVA position statement on infant feeding should be fully implemented across the UK.

Recommendation: Asylum support payments or Healthy Start payments should not be considered sufficient to meet the needs of mothers living with HIV who need support to access formula milk.

Recommendation: In areas that currently have an ad-hoc free formula milk scheme, funding should be protected until national provision is available.

Recommendation: Those responsible for implementing the Baby Friendly Initiative in the UK should give due consideration to UK clinical guidelines that mothers living with HIV exclusively formula feed their babies to prevent transmission. Explicit exemptions should be made so as not to restrict the commissioning and provision of free formula milk to mothers living with HIV.

Recommendation: NHS England should consider funding free formula milk for mothers living with HIV nationally through specialised commissioning as part of the prevention of vertical transmission.

Recommendation: Whilst commissioning at a national level is being considered, local authorities and CCGs (or equivalent) should fill the gap in provision in the meantime.

Recommendation: NHS Health Boards in Scotland and Wales should consider funding free formula milk for mothers living with HIV as a key prevention right.

Recommendation: In the event that future UK clinical guidelines recommend breastfeeding in the case of viral suppression, the NHS should continue to fund free formula milk where needed, based on clinical judgment

(including but not limited to mothers with detectable viral loads, those finding adherence challenging and where fear of transmission causes psychological distress).

Recommendation: Formula milk should be provided to mothers living with HIV to cover the first year of an infant's life.

Recommendation: Formula milk and feeding/sterilising equipment should be provided to mothers living with HIV via the HIV clinic. HIV clinics should determine the best route of provision through consultation with their service users and consideration of local conditions.

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