napwha national association of people with HIV australia

Support for women living with HIV in Australia who are considering infant feeding options – June 2020

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Foreword and acknowledgements

This report summarises preliminary discussions and community consultations regarding a NAPWHA health literacy initiative to be produced in 2021 – initiatives to support for women living with HIV in Australia who are considering infant feeding options.

This health initiative stems from various community consultations were led by Community Advocates – **Diane Lloyd** based in Perth (Western Australia); **Lara Kruizinga** based in south-east Queensland; **Sarah Feagan**, **Precious Mapfumo** and **Emma Sheldon-Collins** in Melbourne – who conducted facilitated group discussions, as well as semi-structured interviews with women living with HIV (WLHIV) between November 2019 to August 2020. These aforementioned community consultations (and HCP consultation) were summarised into reports. They are made available to the Community Advocates of this NAPWHA project, the PLHIV who participated in the consultation, and NAPWHA's membership and associate membership comprised of incorporated people living with HIV (PLHIV) organisations in each Australian state and territory, and in Australasia.

In June 2020, it was established that health literacy gaps were evident in the area of WLHIV and their breastfeeding options. This document summarises meeting notes between Community Advocates, WLHIV community members, Positive Women Victoria staff. They were documented by the NAPWHA Project Coordinator, Saysana Sirimanotham – who further contextualises the rationale for health literacy resourcing.

NAPWHA would like to acknowledge and thank all the people living with HIV (PLHIV) who participated in the consultation for their time and insight; and conveying their lived health experiences.

We recognise that much of the responses to HIV and AIDS relies upon people living with HIV continuing to put themselves forward. This social research is indebted to those past and present.

NAPWHA also thank our community partners in various Australian state and territory for partnering on this project – particularly Positive Women Victoria, in this instance, for their support.

With thanks to **ViiV Healthcare** for providing a research grant making this project possible.

If you would like to speak to us, please use the contact details below:

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Background

The National Association of People with HIV Australia (NAPWHA) is committed to improving HIV-related health care and quality of life outcomes for all people living with HIV (PLHIV) in Australia. This includes promoting, and assisting all PLHIV to engage actively with the HIV care continuum as an evidence-based means to maintain an undetectable viral load and have improved quality of life.

1.1. NAPWHA HIV Health Literacy Framework project

NAPWHA's Health Literacy Framework Project is a three-year initiative (2019–2021) that addresses the role of HIV health literacy in improving HIV-related health care and quality of life outcomes for all PLHIV in Australia. The study is based on the recognition that:

- HIV health literacy in the broader population may not have kept up to date with the profound changes that have characterised HIV and AIDS since the mid-1990s, with consequences for stigma, perceptions of risk, and transmission.
- Changes in HIV notifications (especially over the past decade) have contributed to changes to the make-up of the body positive in Australia.
- Peer-based community organisations such as NAPWHA play an important part in the HIV health literacy ecosystem.

The overall objective is to generate, put into practice, evaluate and revise, and disseminate a 'HIV health literacy framework' to support improved health literacy that would benefit diverse cohorts of PLHIV. Initially, the project has focused on positive women and heterosexual men, and there is a focus too on paying attention to HIV health literacy (or the lack of it) in the general community.

A key intended outcome is that community-based peer organisations, beginning with NAPWHA itself, will enhance their own health literacy so as to have improved conversations with people from groups – now increasing as a percentage of the total body positive – who may have been less visible in the HIV health literacy ecosystem up to the present.

See more: https://napwha.org.au/health-literacy-framework/

1.2 Community Advocates as Health Literacy ambassadors

The NAPWHA-based project team engages the countrywide peer networks to recruit individuals from the key priority populations as research partners. These partners support the development of the health literacy framework – which includes a focus on messages as well as channels of health-related information – and they contribute actively to the research and evaluation associated with the project.

These 'Community Advocates', coming from all over Australia, are provided with training on:

- HIV health literacy and its links with the HIV Care Continuum;
- communication and group facilitation skills; and
- a systems perspective on health literacy interventions.

Working as a team and individually, the community advocates reach out to other women and heterosexual men living with HIV in their regions.

Community Advocates (L-R) – Rita Broughton, Sarah Feagan, Emma Sheldon-Collins, Ron Woods (NAPWHA Training & Research consultant), Lara Kruizinga, (Above) Precious Mapfumo, Diane Lloyd, and Anth McCarthy.

1.3 Using participatory action research

Using participatory action research combined with community development approaches, Community Advocates seek to strengthen peer bonding. Drawing on these developing relationships, they work with the project team to build up a picture of how health literacy accompanies their peers on their journeys into living with the virus. This enables them to consider the strengths and shortcomings of current HIV-related messaging and platforms.

Based on the strengthened peer relationships and engagement with NAPWHA, Community advocates – our research partners – suggest what changes could be made to improve health literacy and then put some of these changes into practice through helping NAPWHA improve its communications with women and heterosexual men. Supported by capacity-building approaches that include training and mentoring, they are also actively involved in evaluation of the project.

1.4 Project activities – Investigative Phase

In the first year of the project, three Community Advocates (Sarah Feagan, Emma Sheldon-Collins, Precious Mapfumo) were appointed by NAPWHA, provided training, and asked to design a process whereby to engage with their networks of women living with HIV. The aims of the community engagement were to investigate HIV health literacy strengths, gaps and needs for women living with HIV (WLHIV) and ask participants to engage in health promoting actions with regards to HIV health.

This initial investigative phase of the project was conducted as a series of facilitated community consultations:

- Two focus groups were run for and by women living with HIV was conducted in Melbourne in October 2019 and Darwin in November 2019. These events were called ‘Let Women Talk’ –

and designed to begin a conversation with women and enable them to share: their experiences of living with HIV and accessing high quality HIV-related information, and to discuss and develop actions to support health literacy in relation to HIV. [1]

- In April and June 2020, in collaboration with Positive Women Victoria two additional community consultation with women were led by NAPWHA and Community Advocates to develop a health literacy initiative focused on supporting women living with HIV in Australia who are considering infant feeding options.

- In the second year of the project, four more Community Advocates (Lara Kruizinga, Diane Lloyd, Rita Broughton, and Anth McCarthy) were appointed by NAPWHA to continue a process of designing a way of broadening the engagement with PLHIV – including women in Queensland and Western Australia[2]. Community consultations were conducted as one-to-one semi-structured interviews during the CoVID-19 lockdowns in Australia from June to September 2020.

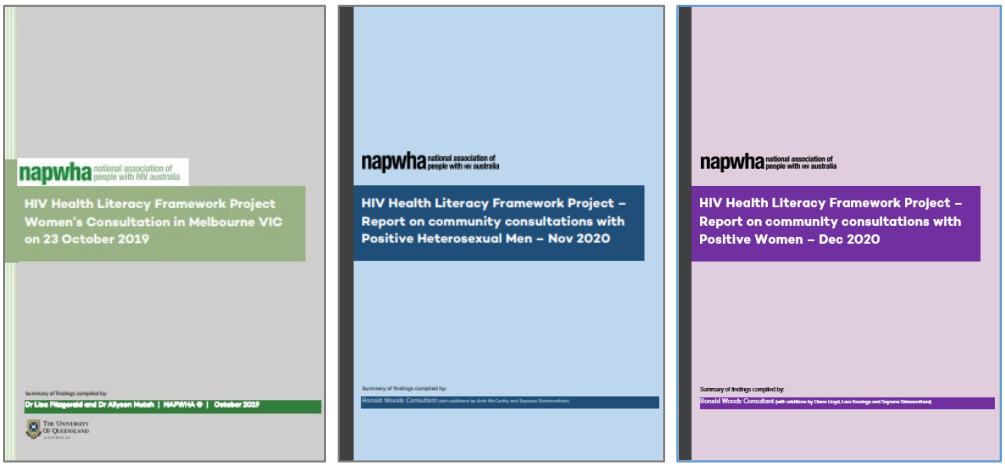
- As this process would then be extended to other communities within the body positive, and the developing Framework shared within the sector, a pilot for investigating the health literacy strengths, gaps and needs of positive heterosexual men was initiated by Anth McCarthy – a HIV Peer Navigator at Living Positive Victoria, based in Melbourne. This initiative provided therefore an early opportunity to apply and refine the Framework, as well as yielding rich qualitative insights.[3]

- In the second phase of the project (2021) – the implementation and evaluation phase – Community Advocates will continue to contribute on NAPWHA-led health literacy initiatives and campaigns which have been informed by the beginning half of the project, or investigative phase.

[1] See project documentation for **HIV Health Literacy Framework Project Women's Consultation in Melbourne VIC** on 23 October 2019 at https://napwha.org.au/wp-content/uploads/2020/02/NAPWHA_HLF2019_Let-Women-Talk-Consultation_WLHIV-Melbourne_REPORT.pdf

[2] See project documentation for **HIV Health Literacy Framework Project – Community Consultations with Women living with HIV in Queensland and Western Australia report** on December 2020 at https://napwha.org.au/wp-content/uploads/2021/04/20210131_NAPWHA_HLF2020_Consultation_WA-QLD-Women-Interviews_v3.pdf

[3] See project documentation for **HIV Health Literacy Framework Project – Community Consultations with heterosexual men in Melbourne report** on November 2020 at http://napwha.org.au/wp-content/uploads/2020/12/NAPWHA_HLF2020_Consultation-with-Positive-Heterosexual-Men_REPORT.pdf



Support for women living with HIV in Australia who are considering infant feeding options

2.1 Preliminary discussions on a NAPWHA Health Literacy initiative

2.1.1 Meeting attendees

Meeting Record – Friday 19 June 2020 – 11AM – 1PM

- Heather Ellis (President, Positive Women Victoria)
- Sarah Feagan (NAPWHA HLF Project Community Advocate)
- Lara Kruizinga (NAPWHA HLF Project Community Advocate)
- 5x WLHIV Community members
- Emma Sheldon-Collins (NAPWHA HLF Project Community Advocate)
- Saysana Sirimanotham (NAPWHA HLF Project Coordinator; meeting notetaker)

2.2 Background to meeting

- In June 2017, Katherine Leane and Jane Costello tendered a submission to the Australasian Society for HIV, Viral Hepatitis and Sexual Health (ASHM) – a **Review of ASHM Antiretroviral Guidelines – US DHHS Guidelines with Australian Commentary: HIV-Infected Women** with regards to postpartum management and infant feeding – on behalf of Femfatales (NAPWHA National Network of Women Living with HIV). The review identified that there are still important gaps in the existing evidence-base and information about the risks and benefits. The result of this work was the impetus for the **ASHM ARV Guidelines Review Sub-Committee: HIV Positive Women and Breastfeeding** to be set up.

- In late-2020, ASHM aims to publish clinical *Guidance for the care of women living with HIV in Australia who are considering infant feeding options* – written by Dr Virginia Furner et al. on behalf of the **ASHM ARV Guidelines Review Sub-Committee: HIV Positive Women and Breastfeeding**.

- In January 2020, the first document version (v 0.1) of this *Guidance* was circulated to NAPWHA, who also circulated it to Heather Ellis and Kirsty Machon (Positive Women Victoria) who made initial comments. NAWPHA added a proposed supplementary foreword, *Letter to the Reader* – and an appendix with content on recommended supplementary resources and contacts to PLHIV organisations. These were added and reverted to the ASHM Sub-Committee secretariat as version 0.2 of the *Guidance*. NB: It was noted by ASHM Sub-Committee that these additions would be considered but have not been formally accepted.

- The **NAPWHA Health Literacy Framework project** commenced in 2019, has appointed HIV Community Advocates – Sarah Feagan, Precious, Emma Sheldon-Collins; and later Lara Kruizinga – to conduct conversations with women living with HIV regarding their health literacy.

These two community consultations – one held with participants in Melbourne (in October 2019; n = 8); and one held in Darwin (in November 2019; n = 6) – concluded that health literacy resources to support women considering breastfeeding options was one of the strongly-identified health literacy content gap among those community participants.

- In May 2020, through project's framework, NAPWHA arranged for 8 community members to add reviews to the ASHM *Guidance* document (v 0.2) – including Community Advocates and WLHIV participants. This review was submitted back to the **ASHM Sub-Committee** consolidating the review from ten WLHIV Community members, including members of Femfatales - – NAPWHA National Network of Women Living with HIV.

- In June 2020, a follow-up community consultation held by NAPWHA was held via Zoom and meeting notes are incorporated into this document. The meeting's aim was to commence preliminary discussions to inform the development of a NAPWHA patient-advocacy resource/s to **support for women living with HIV in Australia who are considering infant feeding options.** Information is summarised in this document.

2.3 Establishing the need for health literacy resourcing

Conversation points have been raised by WLHIV throughout NAPWHA's community consultations inform the need to better improve individual health literacy for women to support their journey in navigating their healthcare and decision making during and after pregnancy.

> *In general, more resources are required that focuses on pregnancy. When I had my pregnancies in [year withheld] and [year withheld] there was limited information for someone who is contemplating pregnancy or who is pregnant. Taking medications [for the baby] was something that I was told of that only late into pregnancy. I still did not know about what was involved with HIV testing [for monitoring the baby] after the birth. There was no understanding [on my part] about how traumatic it would be for the baby. Secondly, the treatments that you are on – that really confused me as well. What research was out there about particular treatments that you are taking and how that affects the fetus? I had to find all of that for myself online.*

> *There needs to be a birth plan – and HIV care coordination fight from day one. After the first trimester, there needs to be clear explanation of pregnancy options, antepartum antiretroviral therapy and prophylaxis options, information about intrapartum care. We are very much left to our own devices. If you do not find yourself a progressive doctor, then you are up s**t's creek.*

I was having the conversation with a nurse the other day saying that there is so much to navigate – and I'm struggling to keep up with all of my appointments because I was undiagnosed for ten years and now, I have a lot of complications from that. But the appointments are ridiculous – you'd think that with a normal pregnancy [a woman not living with HIV] that it is busy anyway but trying to navigate life and all these appointments – I don't know how women do it. I am a nurse by background, and I have an education and speak English as a first language. Anyone else – I don't know how else they do it – because I'm struggling … and so, I think any extra guidance of a care coordinator – like a one-stop shop – that would be so helpful.

My experience was that I was diagnosed HIV when my son was 11-months and I had been breastfeeding that whole time. He is positive but he was born with a HIV-related skin condition, so I know it [vertical transmission] happened in the womb. I was told straight away – stop breastfeeding – and I knew nothing [referring to HIV knowledge at that point in time]. And now, my standpoint in having a positive child, thinking about the frequency of blood tests that the baby has to go through – I KNOW what that looks like and how stressful that is for my child where they are taking 10-12 vials of blood. My son sleeps all day after the blood tests.

A woman considering breastfeeding options who was 26-weeks pregnant says:

My sole decision-making up to now has been made on one doctor's opinion because there is no real resource that I know where to go. It has not been clear. I did not even know that the baby had to be on meds until I was 16 weeks pregnant. I had already told the ID doctor [name withheld] that I was planning to have a baby – and [at that stage] I did not know of this. When was I supposed to know this?

Also, I still kind of do not know how frequently the baby is supposed to get tested [after being born]. I spoke with the nurse, who works with the doctor at [hospital name withheld], who said that we would book you into the pediatrician once you are 30 weeks pregnant and THEN we will go through the steps. I will not know that until the 30-week mark – which is already late. I have already made up my mind by then. I should be having that conversation pre-pregnancy or WITHIN the first 3 to 4 months – earlier rather than later. I want to breastfeed – I'd like to, and I know the advantages of breastfeeding as well, but I probably won't. Navigating the answer is hard when you are keeping a secret.

It is well known that providing safe peer forums for women to exchange discussion among each other are important and useful environments for building health literacy – and HIV treatment literacy.

The below illustrates this – in a dialogue that centres on the topic of ARV prophylaxis that is provided to the mother or child to reduce the risk of HIV transmission during the breastfeeding period:

The meds given – I am not sure that is given whether you do breastfeed or don't. Does anyone [here] know?

It is standard – they are drops – it is AZT and efavirenz – and it's 6 weeks. I did not have any problems with that, and the baby liked it because it was sugary, and they just slurped it up. The amount that the baby is given is quite small.

I do not know anything about the drugs which the baby's going to have. Does it cause reflux? Would it disrupt sleeping?

In seeing my ID specialist, I was told about how AZT works and that babies seem to tolerate it well, but I still remember how I recoiled. But it is still bloody scary to hear that your baby must take this drug [AZT] that has [historically] really damaged people.

My big concern during pregnancy was that I was on Trizivir at the time and I was tolerating it pretty well and they said, don't change. There was very little research around that [treatment] and the foetus. There was one study which they did on rats, where they gave the rats about 50 times the amount and the rats had bone deformity. So, I was really concerned about what would happen on that medication but with my children they are all fine.

Often women are time poor – the demands of having to maintain medical appointments and scheduling the pregnancy care co-ordination can be challenging:

I live about an hour drive to the hospital and need to minimise the time off work. I am trying to synch-up three of my separate medical appointments into one day. It sounds like a pretty simple request – but it was treated as if it was an unreasonable one [by the hospital staff]. To constantly explain that I need to synch-up these appointments because I have so many, every single week – it is ruining my career if I keep taking time off work – it's really hard. Having an idea [of the appointment schedule] so that I could pre-plan from the start, knowing if I would be going in weekly or monthly [or whatever frequency] – it would be a good guide.

There remain some distrusting attitudes towards healthcare providers, whether overtly or covertly expressed, about how legal considerations and mandatory reporting come into play for a WLHIV who breastfeeds but does not engage in healthcare or who may contest a doctor's viewpoint.

There are attitudes that although specific laws do not exist, that clinical guidelines for WLHIV and breastfeeding, have previously been used (and would be used again) as a tool for children to be removed from families by government child protection services agencies (e.g., Family and Child Protection Services):

Certain groups already fear the health, legal and welfare systems. If the first words a health professional utters to their patient is that breastfeeding is NOT recommended, this immediately shuts down the opportunity for a patient-centred collaborative approach. Historically, patients do not question doctors, as "doctor knows best".

Yes – the landscape is changing, however vulnerable communities who, for multiple and complex reasons, fear voicing an opposite view to that which the health professional has already stated. Many WLHIV feel unable to educate and somehow steel themselves against the opposition she will face with health professionals knowing they have a differing opinion on the issue. In my experience, the vast majority of WLHIV will nod and say yes to their doctor, then ask another WLHIV what they know about breastfeeding – because they want to breastfeed. The doctor has already made their position clear – the WLHIV will seek advice elsewhere – and this advice may not be accurate and/or up to date which increases the risk of transmission.

Unfortunately, most WLHIV are not provided with options – I can recount not only my own stories of "now you know you can't breastfeed" multiplied by three pregnancies but hearing that a WLHIV was told otherwise was truly rare. I had the capacity to open up the discussion, however each time I was discouraged, with the health professional shutting down the conversation. Breastfeeding was not an option, despite me sharing evidence of other mothers living with HIV in other parts of Australia, not to mention other parts of the world, being supported to breastfeed. Alternative care was limited so I persisted, but the relationship with my health professional continued to deteriorate because my opinion meant nothing. 35 weeks into my pregnancy I walked out of a Clinic I had been attending for a dozen years, changed my whole care team including the Hospital where I planned to give birth, and contemplated leaving the State, in fact the country. There are many more stories like this, and these stories will continue until there is a stronger message in favour of breastfeeding.

Note – Wording from the *ASHM Guidelines* in the proposed *Letter to Reader* foreword also includes the statement that women from Indigenous communities, refugee women, or women who inject drugs may have well-founded concerns about the involvement of social services. WLHIV have discussed how current categorical advice of abstaining from breastfeeding may preclude women from sharing their feeding preference with providers or cause them to disengage from care because they fear to be judged.

It was raised in one community consultation that it is important for women to see a summary of the positioning of the Australian (ASHM) breastfeeding guidelines alongside other global viewpoints and research – including the WHO, British HIV Association and the Swiss guidelines. These has been included in this document.

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Background on guidelines and breastfeeding

3.1 Background on guidelines and breastfeeding – Global

Guidelines	Country	Guidance on breastfeeding for mothers living with HIV
WHO (in collaboration with UNAIDS, UNFPA and UNICEF) (2010)	Global	• Mothers with HIV should be counselled about the risks and benefits of infant feeding and provided with specific guidance regarding their situation • Mothers who choose to breastfeed should be supported in their choice • Mothers who choose not to breastfeed should be provided with guidance and support around formula feeding • In low and middle income countries exclusive breastfeeding is recommended for the first six months of life
British HIV Association (BHIVA) and Children's HIV Association (CHIVA) (2010)	UK	• In the UK, mothers with HIV are recommended to refrain from breastfeeding from birth regardless of maternal viral load and ART • All mothers with HIV should be supported to formula feed their infant • In rare circumstances where a mother who is effective on combination ART with a repeatedly undetectable viral load chooses to breastfeed then maternal ART should be carefully monitored and continued until one week after all breastfeeding has ceased. Breastfeeding should be ceased by 6 months
Royal College of Obstetricians and Gynaecologists (RCOG) (2010)	UK	• All mothers with HIV should avoid breastfeeding • Women should be given supportive advice about formula feeding
DAIG and Österreichische AIDS-Gesellschaft (2011b)	Germany	• Mothers are advised not to breastfeed, according to WHO guidelines
Grupo de expertas y expertos del plan nacional sobre el sida y de gesida (2011)	Spain	• All mothers with HIV should avoid breastfeeding • Women should be given supportive advice about formula feeding • Formula is provided free of charge through the Public Health System
Ministero della Salute (2011)	Italy	• All mothers with HIV should avoid breastfeeding • Formula is provided free of charge through the National Health System
Prise en charge médicale des personnes vivant avec le VIH, France (2010)	France	• All mothers with HIV should avoid breastfeeding • Mothers with HIV should be counselled about the risks of breastfeeding and be given supportive advice about formula feeding

3.2 Background on guidelines and breastfeeding – ASHM/Australia

ASHM (2020 TBC) * A draft version of the clinical Guidance for the care of women living with HIV in Australia who are considering infant feeding options – written by Dr Virginia Furner et al will be published by ASHM in late 2020 (TBC). A draft version was made available to NAPWHA.	Australia	• Mothers with HIV should be informed that breastfeeding is not recommended for their babies even where optimal vertical transmission strategies are in place and despite recommendations by the WHO that breast feeding is the best option for all infants. • All women living with HIV who are planning a pregnancy or are pregnant, should be provided with counselled about risks and benefits of infant feeding, so that they can make an informed choice regarding their options free from bias and coercion and in a context of safety between themselves and their health care provider.

3.3 Background on guidelines and breastfeeding in other resource-rich settings – the current picture in UK

Referenced from **Breastfeeding with an undetectable viral load: some insights into the current UK situation** published in AIDS Map by **Michael Carter** on 26 April 2019

- The current rate of mother-to-child, or vertical, HIV transmission in the UK and Ireland is below 0.3%. The British HIV Association (BHIVA) guidelines **recommend that HIV-positive mothers formula feed their infants**, eliminating postnatal transmission. However, they also note that women with an undetectable viral load and good adherence who opt to breastfeed should be **clinically supported** to do so.

    - Francis K et al. *BHIVA guidelines and breastfeeding in the UK – the current picture*. 25th Annual Conference of the British HIV Association, Bournemouth, abstract O04, 2019.

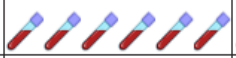
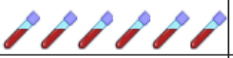
British HIV Association guidelines for the management of HIV in pregnancy and postpartum 2018 (2020 third interim update) include for breastfeeding guidelines:

- Recommended monthly in-clinic follow-up and review of HIV RNA viral load testing for the mother and baby – during, and for 2 months after stopping breastfeeding

Appointments

You and your baby will have extra appointments and more blood tests if you decide to breastfeed. This is to make sure there is no HIV detected in your blood and to check your baby's health and make sure she or he remains HIV negative.

The number of blood tests and checks you and your baby will have depends on how you decide to feed your baby:

Timing of Bloodtests	Breastfeeding woman	Breastfeeding baby	Formula fed baby
At birth			
Every 4 weeks as long as you are breastfeeding	For example: Six blood tests if breastfeeding for 6 months (1 per month) 	For example: Six blood tests if breastfeeding for 6 months (1 per month) 	
6 weeks after birth			
12 weeks after birth			
4 weeks after you have stopped breastfeeding			
8 weeks after you have stopped breastfeeding			

    - Table 2 (above) taken from BHIVA leaflet: *General information on infant feeding for women living with HIV* [PDF]

- Maternal antiretroviral therapy – rather than infant pre-exposure prophylaxis is advised to minimise HIV transmission and safeguard mothers' health

- Infant HIV antibody testing at age 18–24 months
- Breastfeeding for as short a time as possible – exclusively for the first 6 months, and cease if signs of breast infection/mastitis or if mother or infant has gastrointestinal symptoms

Research on women's attitudes towards breastfeeding was presented to the recent 25th British HIV Association (BHIVA) conference

- Insights into the attitudes of childbearing HIV-positive women were gleaned from a study conducted between 2017 and 2018. A total of 94 HIV-positive women in the final trimester of pregnancy or who had recently given birth took part; 92% had an undetectable viral load (one woman had low but detectable viral load, data were lacking on the other participants).

- Over a third of HIV-positive women in the final stages of pregnancy or who have recently given birth would like to breastfeed. But the study also showed that only 27% of women thought it was safe for a mother to breastfeed if her viral load was undetectable.

Some women choose to breastfeed for the following reasons:

'I wanted to feel close to my baby'

'I know there are health benefits to breastfeeding'

'I breastfed my last baby and he is fine'

'Formula is too expensive'

'My mother in law keeps making me breastfeed'

'My husband does not know about my HIV and I do not want him to find out'

'I was told where I used to live that breastfeeding while taking treatment is safe'.

'Breastfeeding is more convenient'

'My baby and I are going to a country where and I can't always get formula and do not know if the water is always clean'.

- Answers also provided some insights into the pressure on HIV-positive mothers to breastfeed. Two-thirds said they had lied about their reasons for not breastfeeding and 62% reported that they had been questioned by friends, family, or members of their community for not breastfeeding.

Peer supporter M.M. (HIV+ 25 years) suggested these responses if someone asks why you are bottle feeding:

'I don't want to risk passing on HIV or my meds to my baby'.

'Breastfeeding just didn't work for us'.

'I am taking antibiotics'.

'He started off on formula so we just stuck with it'.

'The health visitor said she is doing great and to just keep doing what I am doing'.

'This means her Dad can help out more'.

'I was told skin-to-skin is just as good'.

'It's a personal choice'.

'I have inverted/painful nipples'.

'I had problems with breastfeeding previously'.

'I prefer the privacy'.

Whatever you decide, agree with your partner what you will say to friends and family – everyone is more likely to accept your reasons if they are always the same.

- Table 1 and 2 (above) taken from BHIVA leaflet: *General information on infant feeding for women living with HIV* [PDF]
- Nyatsanza F et al. *38% of child bearing women with HIV in the UK would like to breastfeed: PACIFY STUDY*. 25th Annual Conference of the British HIV Association, Bournemouth, abstract O05, 2019.

3.4 Background on guidelines and breastfeeding in other resource-rich settings – the current picture in Switzerland

Referenced from **Is breastfeeding for HIV-positive mothers now recommendable?** published in Swiss Medical Weekly by **Gamell Anna** on 27 July 2018

- In their viewpoint article Is breastfeeding an equipoise option in effectively treated HIV infected mothers in a high-income setting? published in *Swiss Medical Weekly* on 24 July 2018, Kahlert et al. suggest that it is time to rethink the hard-line counselling against breastfeeding for HIV-infected mothers in Switzerland and, implicitly, in all Western countries.

  - *Is breastfeeding an equipoise option in effectively treated HIV infected mothers in a high-income setting?* Swiss Med Wkly. 2018;148:w14648
    DOI: https://doi.org/10.4414/smw.2018.14648

- The authors define a situation which they call **the optimal scenario**: the pregnant woman is
  (i) adherent in taking her ART
  (ii) under regular care, and
  (iii) has a suppressed HIV viral load of <50 RNA copies/ml throughout pregnancy and breastfeeding

  When these criteria are met, the theoretical risk of vertical transmission is virtually zero.

- They argue that this is a situation of **clinical equipoise**, where the residual risk of MTCT through the breast milk is balanced with the general benefits of breastfeeding and propose a **shared decision-making process** to choose the form of infant feeding. They suggest a list of topics on which to provide unbiased information for the mother to enable her comprehensive understanding of one or the other decision.

- It is stated: *Although breastfeeding still should not be actively recommended in Switzerland, any mother (WLHIV), regardless of her geographical and cultural background, who decides to breastfeed should be supported by the best strategy to achieve optimal medical care for both herself and her child.*

- The article by Kahlert et al. can be very helpful to clinical teams that feel ready to be more flexible with the recommendations they provide to pregnant women living with HIV. In that manuscript they will find a guideline to having a comprehensive discussion with mothers about risks and benefits of breastfeeding and to establish a schedule of clinical and laboratory follow-up of the mother-infant pairs where the mother opts to breastfeed.

- An important issue that will need further discussion is whether clinicians should be encouraged to discuss risks and benefits of breastfeeding with all pregnant women meeting the "optimal scenario" or only with those who, besides meeting the "optimal scenario", verbalise their wish to breastfeed. On one hand, this may raise a concern of an increase in the transmission risk; on the other hand, keeping the shared decision-making process to only those who express their wish to breastfeed seems paternalistic.

- This viewpoint states: *It is time that high-income countries move towards less rigid recommendations about infant feeding. Some families affected with HIV are ready to understand the risks and benefits of breastfeeding their HIV-exposed infants. Therefore, healthcare providers must be able to offer them unbiased information to empower their comprehensive understanding of one or other decision.* ***If, after a shared decision-making process, the mother's choice is supported with a nonjudgmental attitude and close monitoring is arranged, the best care for her and her infant will be guaranteed.***

Table 1

Guidance for a shared decision-making process to decide on breastfeeding by HIV-infected mothers fulfilling the "optimal scenario".

1. Requirements	An "optimal scenario" is when the pregnant woman is (i) adherent in taking her cART, is (ii) under regular clinical care, and (iii) has a suppressed HIV pVL of <50 RNA copies/ml throughout pregnancy.
	All the involved healthcare providers should agree on an open, non-judgmental and unbiased approach towards breastfeeding.
	Understand the woman's preference before discussing risks and benefits.
	Discuss arguments for and against breastfeeding including open questions and admit limitations of medical knowledge (see listings under 2 and 3 below).
	Inform the woman that the whole HIV care team accepts whatever the decision is and this will not affect the quality of the HIV management offered to her.

2. List of potential RISKS associated with breastfeeding	HIV transmission to the child cannot be ruled out.
	(i) Transmission through breastfeeding in the range of 0.3–0.9% (6–24 months of breastfeeding) has been observed in the past when women were under effective combined antiretroviral therapy (cART) during pregnancy and the breastfeeding period.
	(ii) There is no formal study evaluating the risk of MTCT by HIV-infected mothers who are under suppressive cART.
	(iii) Even if we are not aware of a single case of MTCT under the "optimal scenario" we cannot exclude the possibility that such a case did or might happen.
	(iv) Even though the risk of transmission may be very low, if it occurs in a single child, the consequences of HIV transmission are lifelong for the child
	Postpartum is a vulnerable period (e.g., irregular sleep, elevated risk for mood disorders) for women with the risk of impaired adherence and consequently increased pVL. In this period particularly, support of adherence to cART is important.
	Longer exposure to maternal antiretroviral drugs; although breast milk concentrations are low, toxicity cannot be absolutely excluded.
	Episodes of mastitis might increase the risk of transmission.
	An increased risk of HIV MTCT has been observed in breastfeeding untreated HIV-infected mothers when breastfeeding was accompanied by solid food (i.e., mixed feeding). There are currently no data to support an additional risk in the "optimal scenario" but it cannot be excluded. Exclusive breastfeeding during the first 4 months is generally recommended in Switzerland.
	The role of cell-associated virus in breast milk as an additional possible risk is not fully understood.
3. List of potential BENEFITS arguing for breastfeeding	Recommendations to breastfeed during the 6 months postpartum exist in many European countries including Switzerland
	Parents consider breastfeeding a simple, easy and free way of providing nutrition to the infant AND/OR psychologically essential for infant care and development.
	Breastfeeding has beneficial effects for the child (though not formally proven for children of HIV-infected mothers), such as:
	(i) The human microbiome is established normally with possible beneficial health consequences; e.g. lower risk to develop allergies, overweight and diabetes.
	(ii) Anti-inflammatory and anti-infective components in breast milk might have beneficial effect for immune-response and immune-tolerance which are important to prevent the development of allergies or infectious diseases.
	Beneficial effects of breastfeeding for the mother include:
	(i) Improved postpartum recovery with breastfeeding helps in the involution of the uterus and reduces postpartum depression.
	(ii) A beneficial role of breastfeeding to reduce the future risk to develop breast cancer and on glucose homeostasis and protection against type 2 diabetes.

cART = combined antiretroviral therapy; HIV = human immunodeficiency virus; MTCT = mother-to-child transmission; pVL = plasma viral load

Is breastfeeding an equipoise option in effectively treated HIV infected mothers in a high-income setting? Swiss Med Wkly. 2018;148:w14648
DOI: https://doi.org/10.4414/smw.2018.14648

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Proposal for NAPWHA Health Literacy resource development in 2021

NAPWHA proposes the development and publishing of three patient factsheets:

PDF Factsheet 1 – General information on infant feeding for women living with HIV

Content loosely based on content from the **BHIVA factsheet** (see: attachment) but adapted with information from the ASHM Guidelines and Australian context:

- The ASHM recommended statement upfront – what is the evidence-base informing that?
- What you need to know if you are considering breastfeeding your baby
- What you need to know if you are considering formula feeding your baby
- Information about donor breast milk and milk banks
- What would scheduling/timing of medical appointment look like in antepartum and postpartum care AND what you could expect regarding number of blood test for you and your baby
- Your medicines in your breast milk
- Child protection concerns – including suggested responses if someone asks why you are bottle feeding
- Helplines and further links to support (e.g. Private lactation consultants)

PDF Factsheet 2 – HIV and breastfeeding your baby

Content loosely based on content from the **BHIVA factsheet** (see: attachment) but adapted with information from the ASHM Guidelines and Australian context:

- The *Safer Triangle*
  - No virus
  - Happy tums
  - Healthy breasts for mums
- Formula feeds for back-up – if a side of the *Safer Triangle* breaks
- Introducing your baby to food – what you need to know
- How to stop breastfeeding
- Help with breastfeeding problems for women living with HIV
- Healthy breasts for mums
  - Mastitis
  - Cracked or bleeding nipples
  - Thrush
  - Diarrhoea and vomiting

PDF Factsheet 3 – Building a relationship with your doctor or healthcare provider: HIV and breastfeeding

This is a working title of what is essentially a 1-page double-sided patient-advocacy tool which provides a practical step-by-step guide of what to know and plan for having a conversation; providing strategies of what to do; where to seek other support). It would be based on *BHIVA's Ten safe breastfeeding rules* (see: Table 2) and promote what patient-centred care approach is.

1 **Understand your own preferences before you tell your HIV team that you want to breastfeed** – there are many benefits to breast feeding. Many parents consider breast feeding a simple, easy and free way of providing nutrition to a baby AND/OR psychologically essential for the care of an infant and the baby's development.

You may be advised that HIV transmission (vertical transmission) to your baby cannot be ruled out – and that breast feeding may not be as safe as formula feeding. However, it is the healthcare provider's job to offer you support and unbiased information to help you understand what is considered best care for you and your baby. 10-12.

2 **Get breastfeeding advice from someone who knows you are living with HIV** – the advice is sometimes different for women living with HIV than those without HIV.

In Australia, relationships with your doctor should be *patient-centred* and you and your HIV care provider are equal partners in the shared decision-making process. If you are unhappy with the care that you are receiving, you always have the right to change, or *shop around* for other healthcare providers.

If you are unsure, you could get advice and talk through it with other women who have had experience finding a doctor that works for them via TIM Women, Positive Women Victoria.

If you choose to breastfeed, your HIV team may inform you with of a list of recommendations, including:

3 **100% adherence to ART drugs** 16, 17.

4 **Stop all breastfeeding as early as possible** 10, 15, 47.

5 **Breast milk only** – no other food or drink (apart from vitamins and medications as advised) for the baby 13.

6 **Prepare for when you might have to stop breastfeeding** – consider building up a supply of expressed breastmilk and have an emergency set of bottles, formula and cabergoline prescription for established breastfeeding 48.

7 **Do not breastfeed if** you develop mastitis, cracked bleeding nipples or nipple thrush 17, 35, 36.

8 **Do not breastfeed if** you or your baby develops diarrhoea or vomiting 17.

9 **Only breastfeed when you have an undetectable viral load** 13, 16, 17.

10 **Do not return to breastfeeding once the baby starts formula feeding** 11.

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Appendix

5.1 Document Control

Revision History

The following changes have been made to this requirements specification:

Version	Prepared by	Date	Description of Change
0.1	Saysana Sirimanotham	20-Jun-2020	Document provided

5.2 Related Documents

- HIV Health Literacy Framework Project Literature Review and Community Training Handbook (July 2019) [Author: Ronald Woods]
- NAPWHA HIV Health Literacy Framework Project – Evaluation Framework (June 2019) [Author: Ronald Woods]
- HIV Health Literacy Framework Project Healthcare Providers Consultation in Cairns QLD on 23 August 2019
- HIV Health Literacy Framework Project Women's Consultation in Melbourne VIC on 23 October 2019
- **HIV Health Literacy Framework Project Women's Consultation in Darwin NT** on 7 November 2019
- HIV Health Literacy Framework Project – Community Consultations with heterosexual men in Melbourne report – November 2020
- HIV Health Literacy Framework Project – Community Consultations with Women living with HIV in Queensland and Western Australia report – December 2020
- HIV Health Literacy Strategies for culturally and linguistically diverse (CALD) women living with HIV – Apr 2021

5.3 Organisational Contact Details

The community consultation is being carried out by the following people:		
Role	**Name**	**Organisation**
Community Advocates / Research co-designers	Rita Broughton Sarah Feagan Lara Kruizinga Diane Lloyd Precious Mapfumo Anth McCarthy Emma Sheldon-Collins	NAPWHA In partnership with Positive Women Victoria. Living Positive Victoria Queensland Positive People NTAHC
Research	Ronald Woods Consultant	
Project Co-ordination	Saysana Sirimanotham	NAPWHA
Research funder	The study is being run by the National Association for People with HIV Australia (NAPWHA) in partnership with Living Positive Victoria, Positive Women Victoria, QPP. ViiV Healthcare are providing financial support.	