

# The impact of free formula milk provision for parents living with HIV

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In relation to this presentation I declare that we have no conflicts of interest.



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## Who we are

The Food Chain exists to ensure people living with HIV in London can access the nutrition they need to get well, stay well and lead healthy, independent lives.

We deliver meals and groceries, offer cookery and nutrition classes and communal eating opportunities to people living with HIV in London and their dependents.

We have our own kitchen space in King's Cross.

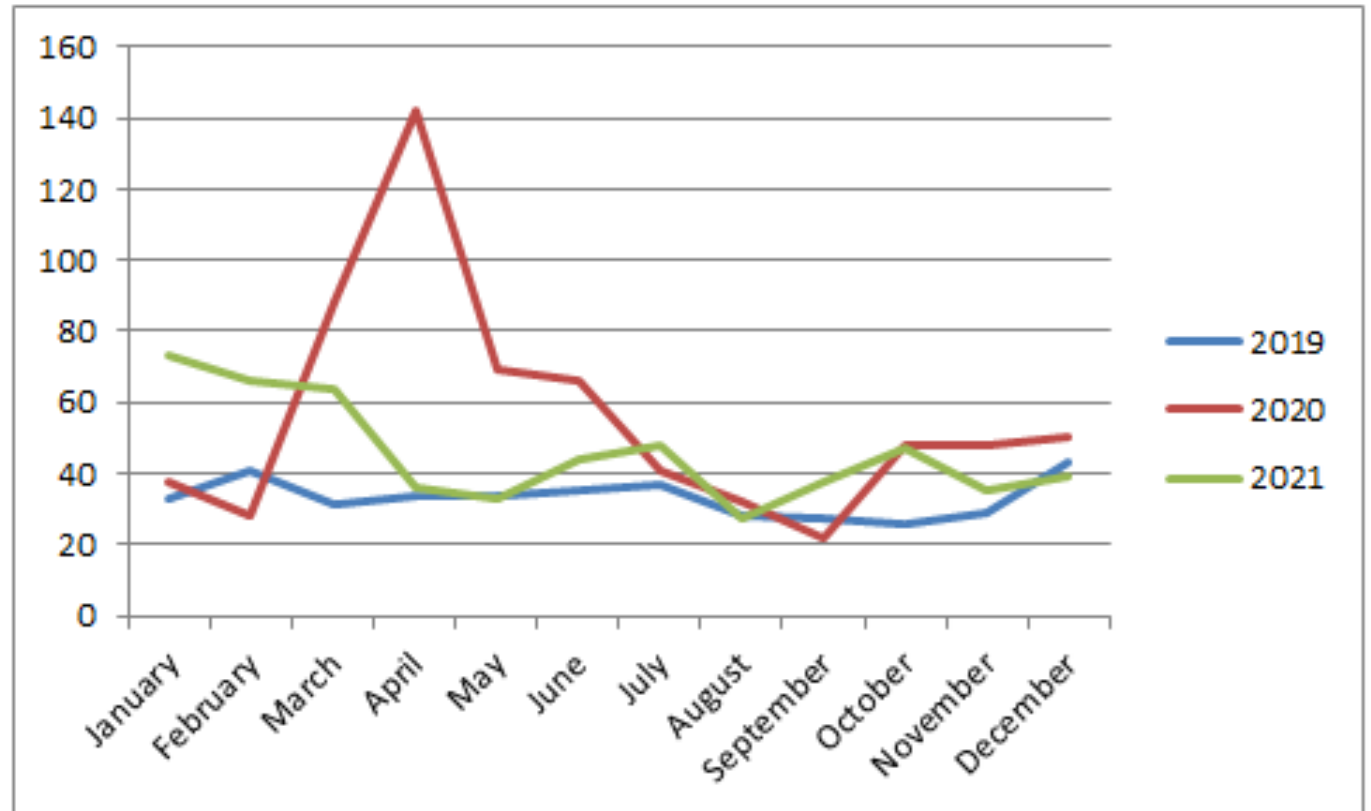
# What we do



# What we saw in 2020

Increased need triggered by pandemic:

- Shielding
- Closure of other support services
- Lack of engagement with clinics
- Anxiety & avoidance of busy places
- Problems accessing statutory provision
- Enduring or new financial hardships
- NRPF



# What we did

Regardless of the time-limited nature of our food support, we will provide enough formula milk to feed a new/expecting parent's baby until they are 12 months old.

# How we implemented

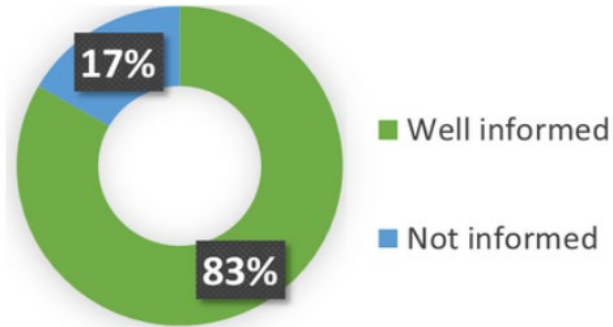
- Identified need
  - Service User and/or referrer
  - Establish brand
  - Record baby DOB
- Monthly deliveries
  - After groceries end, formula deliveries continue
- Monitoring
  - Dedicated list monitored by 1 staff member
  - Mid point assessment, end of service assessment
- Follow on
  - Advice on weaning
  - Recipes & resources



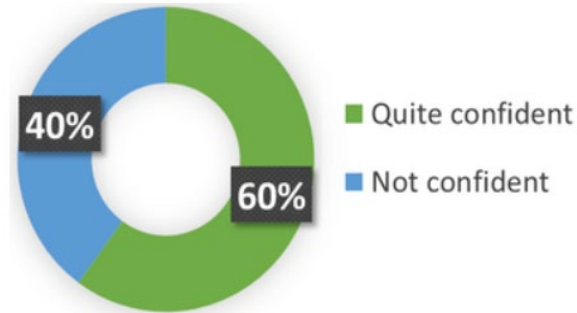
Figure 1: Number of monthly formula milk boxes as per baby's age

# What we found

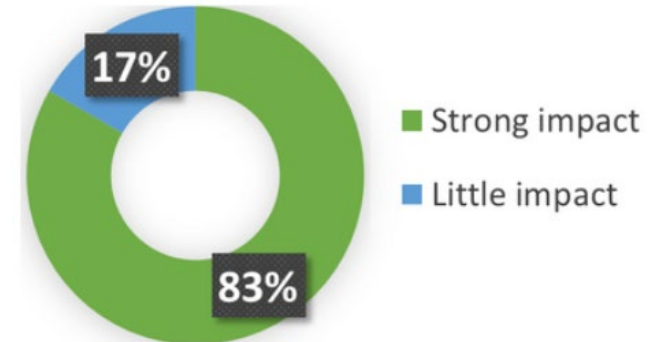
How informed did you feel about options for feeding your baby?



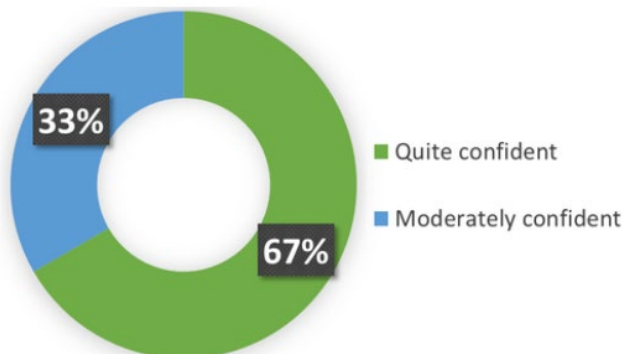
How confident were you about being able to access formula milk before receiving our support?



If you had to spend money on formula milk, how much impact do you think it would have on your household budget?



How confident do you feel about using formula milk?



How much impact has our formula milk provision had on you and your family's quality of life?





## 1

### Parents feel they receive mixed messages on feeding options

“Different departments in the same hospital gave different advice. The maternity department was completely against breastfeeding. But the HIV clinic asked me why I wanted to breastfeed and support my decision. They advised and said that if my viral load became detectable, I would then have to formula feed.”

## 2

### Statutory provision is often inconsistent

“The midwife at \*\*\* provides formula every month until the baby is 1yr old, but I have to call and ask. Before delivery, I received 2 boxes of Aptamil 1 and then 6 boxes when my baby was 1 month. I kept on receiving more boxes but only when I go in for the visit.”

“The midwife didn't know about access to formula milk. The \*\*\* hospital post-natal ward only gave me liquid formula in the bottle, which I could use as much as I needed, but they didn't let me take it home. When I left, they only gave me 1 bottle so I could feed my baby in the parking lot. I had to buy formula when I got home.”

## 3

### Mothers often experience trauma related to formula feeding

“I use aptamil, but the hospital didn't let me use it, even though I brought my own [...] and they didn't have hot water. They also gave me very little formula for feeding, but my son was still hungry. I had to keep on ringing the bell to ask for more, I felt like I was bothering them, but I didn't want my son to go hungry. Some nurses were lovely, they would bring more formula, but not everyone did the same. They had also given me pill to stop my breast milk so I had to rely on formula milk.”

“The hospital gave me formula milk but to get it I had to go to the reception and ask for it. It was difficult for me to walk to the reception and back after my operation. And they would only give me one bottle, if I asked for more they were unhappy. My baby needed a lot of formula milk so I had to walk back and forth to get formula.”

4

## Financial barriers limit access and impact mental health

- “ I get sure start (Healthy Start) vouchers to buy milk and vegetable, however since formula milk is expensive, I must use 4 vouchers (around £3 per voucher) per month to buy 1 box of formula, which is not enough. So, I must choose between milk and vegetable or formula milk.”
- “ I don't have to make that choice between food or formula or choose to buy things for my other kid. I do not need to prioritize one thing over the other.”

5

## Formula feeding can carry stigma

- “ They (friends) made me feel uncomfortable and ask me why I use formula, I just tell them about a condition, I don't say anything specific.”
- “ A lot of people asked me why I don't breastfeed. I just tell them that I don't produce any milk.”
- “ When someone asks me why I use formula or say that I should only breastfeed until 6 months, can't tell everyone why you decide to do it, it's personal.”

# Our approach

## Guidance on formula feeding:

- The World Health Organisation guidance (2016)
- The British HIV Association (2018)

## Formula option has a financial barrier

- The National AIDS Trust *Access to Formula Milk* policy briefing (2017)

1. The Food Chain addresses formula milk insecurity
2. Service User-led approach
3. Collaboration with referrers

## Our conclusion



The value of free formula milk provision is very significant for our HIV+ parents. We are committed to continuing this service for as long as we are able.

Thank you to The Food Chain's Service Users for their honesty, bravery and support of this research

# Questions

## References

- 1 World Health Organization, United Nations Children's Fund. Guideline: updates on HIV and infant feeding: the duration of breastfeeding, and support from health services to improve feeding practices among mothers living with HIV. Geneva: World Health Organization; 2016.
- 2 Gilleece Y, Tariq S, Bamford A et al. British HIV Association guidelines for the management of HIV in pregnancy and postpartum 2018. *HIV Med* 2019; 20 Suppl 3: s2-s85.
- 3 National AIDS Trust. *Policy briefing: access to formula milk for mothers with HIV in the UK*. 2017