BHIVA guidelines on the management of pregnancy for women living with HIV

Public consultation comments

Compilation of all comments received via the BHIVA website. The writing group thanks everyone who replied to the consultation. The guidelines have been revised based on the comments unless otherwise stated.
19/2/18

Contents

	Name	Affiliation	Comments	Writing group response (The guidelines have been revised based on the comments unless otherwise stated)
1.	Gary Brook	LNWUH Trust	Thanks. Very comprehensive guidelines. Just a few points to do with routine monitoring. In sections 5.2.3-5.2.6 you continue to recommend CD4 and viral load at delivery, LFT at every antenatal visit after starting ART and consider TDM if the VL is not suppressed. In the original guidelines these were not justified or referenced and same applies to the new guidelines. I can see no advantage in doing a CD4 and VL at delivery in women stable on treatment. Surely the LFT testing frequency has to be fixed and not dictated by the frequency of antenatal visits. What happens if very frequent visits are required? TDM has very little place nowadays on monitoring failure, as discussed in the BHIVA monitoring guidelines. All the best, Gary	Frequency and nature of investigations reviewed and agreed by writing group
2.	Pamela Morrison		Thank you very much for letting me know that the BHIVA revised guidance on the management of HIV infection in women, and preventing transmission to their infants, is now open for consultation. I very much appreciate the opportunity to comment on the sections which relate to breastfeeding in this very comprehensive document. It is so important that mothers living with HIV can receive sufficient information to make a decision about the most suitable feeding method for their babies in their particular circumstances. I continue to work with a few mothers who really have their hearts set on breastfeeding and are able to obtain the support of their HIV clinicians and their own OBs and the baby's paediatricians, so I am very interested in the information set out in the BHIVA document. A clarification of BHIVA guidance is also very welcome in order to help dispel the continued myth-information attributed to BHIVA given by other organizations. Two examples I have recently come across are: • I-Base, Swahili booklet on pregnancy, (Dec 2017) http://i-base.info/pregnancy-swahili/ It is particularly disappointing to see from this booklet that formula-feeding is so strongly recommended for African mothers (who would expect to breastfeed in their countries of origin) and in a language which would not be understood by most people living in the UK. I just happened to be brought up in East Africa where Swahili is the lingua franca and what I didn't understand I was able to look up on a translation website. • National AIDS Trust guidance on HIV and infant feeding https://www.nat.org.uk/sites/default/files/publications/Access%20to%20Formula%20Milk%20Briefin	No action required This is cited as it is an important policy briefing

			g%20FINAL.pdf issued in April 2017, shown to me by one of my IBCLC colleagues in early January 2018, contains misleading information. Attached please find a paper which I wrote with a colleague for Essentially MIDIRS in Dec 2014 in an effort to dispel some of the misconceptions surrounding breastfeeding in the context of HIV. I will certainly send you my comments on the current draft document before your deadline of 19 February, and am very grateful for the opportunity to do so.	in terms of funding infant formula We did not have access to this paper but our guidelines our based on a full review of current peer-reviewed evidence
3.	Pamela Morrison	International Board Certified Lactation Consultant	Dear Jacqueline and Yvonne Further to our previous emails, I now attach my response to the consultation on the BHIVA Pregnancy (and Postnatal) Guidelines, together with supporting documents, as follows: 1 . My comments (dated 4 February 2018) on the British HIV Association guidelines for the management of HIV infection in pregnant women 2018. 2. Lactation Consultants of Great Britain, the Crucial Role of Breastfeeding 3. Lactation Consultants of Great Britain, Who's Who in Breastfeeding (breastfeeding support in the UK) 4. Excerpts from the World Alliance for Breastfeeding Action draft 2018 Updated HIV Kit (in press) 5. P Morrison, Pasteurized Breastmilk as a Method of Feeding HIV-exposed Babies, with P Reimer review, 1 May 2017 6. P Morrison, Suppression of Lactation following Birth, updated October 2017 7. P Morrison, Lactation Management for Mothers, updated Sept 2013 Thank you very much for giving me the opportunity to participate in the public consultation on this very important document. Please don't hesitate to contact me if you need clarification or any more information on the points that I have responded to. Warm regards Pamela Morrison	2–4. The aim of the guidelines is not to provide an overview of the benefits of breastfeeding (which we fully accept) but to provide guidance on infant feeding with regard to minimising HIV transmission. A wider discussion of the benefits of breastfeeding is beyond the remit of these guidelines. 5. Not recommended in BHIVA guidelines as difficult to do in practice. 6. We have included a section on cabergoline
4.	Dr Natalie Shenker	Hearts Milk Bank CIC	The Hearts Milk Bank was established as a not-for-profit organisation to provide assured, equitable supplies of donor milk to NICUs, and meet unfulfilled needs for donor milk beyond the neonatal unit. Several countries with entrenched milk banking networks already centrally fund donor milk provision for babies whose mothers have HIV. Donor milk, even after heat treatment, contains numerous	This is beyond the scope of the guidelines

			functional antimicrobial components, including lactoferrin, lysozyme, human milk oligosaccharides, and epidermal growth factor, and an array of human-specific fatty acids that support the development of the infant brain, none of which are found in infant formula. In the past, supply issues have limited donor milk as a viable option in the UK, but the advent of large- scale regional milk banks is changing the landscape of access. We propose that donor milk should be available to babies on a similar funding model to that provided through voucher schemes for free infant formula, and that the consultation should be extended to include the UK Association for Milk Banking, of which I am a Trustee.	
5.	Helen Colver	Luton Sexual Health	In section 6.4.1 under pharmacokinetics TDF has been used instead of TAF: Tenofovir alafenamide (TAF) is a newer version of tenofovir-DF and whilst there are limited data on the safety and pharmacokinetics of TDF; no signals for concern with regard to birth defect have been seen [36]. The Writing Group does not recommend its routine use in pregnancy until further data are available. All women who conceive on TDF should have a discussion regarding this and consideration should be given to switching women who conceive on TDF if necessary to an alternative NRTI regimen.	This has been corrected Guidelines are in agreement with this and we have clarified the wording
6.	Emma Wainwright	Royal Berkshire Hospital	1. It is recommended that women conceiving on a cART regimen should continue this. Exceptions are: non-standard regimens, for example protease inhibitor (PI) monotherapy, regimens that have been demonstrated to show lower pharmacokinetics in pregnancy and protease inhibitors demonstrated to increase risk of pre-term delivery. These should be modified to include (depending on tolerability, resistance and prior antiretroviral history) one or more agents that cross the placenta. **WHAT EXACTLY IS MEANT BY PIs WITH INCREASED RISK OF PRE-TERM DELIVERY? WHICH ONES SHOULD BE SWITCHED? 2. Tenofovir alafenamide (TAF) is a newer version of tenofovir-DF and whilst there are limited data on the safety and pharmacokinetics of TDF; no signals for concern with regard to birth defect have been seen [36]. The Writing Group does not recommend its routine use in pregnancy until further data are available. All women who conceive on TDF should have a discussion regarding this and consideration should be given to switching women who conceive on TDF if necessary to an alternative NRTI regimen. **SHOULD THIS READ TAF NOT TDF.	1. PTD section is now clearer and specifies which PIs are more likely to cause PTD 2. This has been corrected
7.	Laura Kearney	UK Drugs in Lactation Advisory Service (NHS)	There seems to be very little emphasis on drug exposure in breast milk. Whilst clearly the mum needs to continue with her regimen if she chooses to breastfeed, a risk assessment should be performed as to the safety of exposing these medicines to the infant via milk. There will be risk of certain side- effects happening in the infant and specific monitoring requirements. This should all form part of the risk assessment and decision as to whether mum wants to expose the child to the breast milk, not	Now added a sentence on potential toxicity to infant

			only from the HIV viral load point of view, but also the medications the milk contains. We are an evidence based service run by highly specialist pharmacists providing advice on the use of medicines during breastfeeding. We are commissioned by NHS England and are part of the UKMi and SPS Networks: www.sps.nhs/ukdilas. We would be happy to be involved more if you felt this was appropriate	This has been added
8.	Annemiek de Ruiter	ViiV HC and GSTT	Congratulations on a job well done. I know how much work this involves. I have 2 practical suggestions around breastfeeding: 1.I agree that we should still recommend formula feeding and found the patient information at the end of the guidelines very useful. However I would suggest that the topic of breastfeeding including the possibility to do so if the situation is right and the woman wishes to do so should be raised early in pregnancy. I think that what happens in practice is that it isn't raised, and then the woman herself may raise it later or not at all. Better to have plenty of opportunity to discuss throughout the pregnancy than her raising it for the first time at 30+ weeks. We have certainly found that more useful. 2. Where breastfeeding does occur, there is some confusion around weaning based on the fear around mixed feeding. What happens is that women are advised to go straight onto formula with very little if any weaning. I am not sure that fear is entirely logical in the face of a fully supressed viral load and it is certainly very uncomfortable. Yes, keep it short, but let's be practical.	1. This has been added 2. This has been addressed
9.	Jane Shepherd	UK-CAB	Only small points: Page 21, 4.1.2 2nd para. "Women from communities with high levels of HIV awareness" The language implies they are well informed when often it is the opposite. Maybe "communities where HIV is more common". 6.2.1 "All pregnant women, including elite controllers should start ART during pregnancy …" If this is an addition to this guideline there should be a reference to the discussion on elite controllers. I followed ref 7 and couldn't find anything relevant – if it's there, then it wasnt easy to find.	This has been changed as suggested Small section on elite controllers reintroduced for clarity
10.	Justin Daniels	North Middlesex University Hospital	I am worried about the increased complexity of ARVs for newborns - I wonder if there is evidence of harm if all low risk babies get 4 weeks ARVs? I am happy with the statements about breast feeding - I thought these might be more difficult otherwise I really like it - lots of things that have needed discussion are now clarified	ARV complexity is reduced for newborns to low-risk women as now 14/7. Triple regimen recommended is unchanged

11.	Helen Peters	National Study of HIV in Pregnancy & Childhood	Any reference to this paper should read: Peters H, Thorne C, Tookey PA, L B. National audit of perinatal HIV infections in the UK, 2006–2013: what lessons can be learnt? HIV Med 2018 This has now been published.	This has been updated
12.	Susan Bewley	Kings College London	I have looked at the guidelines manual, the draft consultation and appendices. You have a policy about declarations of interest. However, I cannot find any reference to the DOIs of the authors in this consultation version. Would it be possible to direct me to where I can find this information please?	Declarations of interest are published in conjunction with the guidelines as per BHIVA policy
13.	Maquilla Gemma Protacio	herbal	I am indeed very happy for my life; My name is Maquilla Gemma Protacio, I never thought that I will live on earth before the year runs out. I have been suffering from a deadly disease (HIV) for the past 5 years now; I had spent a lot of money going from one places to another, from one church to another, hospitals have been my every day residence. Constant checks up have been my hobby not until last Month, I was searching through the internet, I saw a testimony on how DR. ALI EKER helped someone in curing her HIV disease, quickly I copied his email which is (). I spoke to him, he asked me to do some certain things which I did, he told me that he is going to provide the herbal to me, which he did, then he asked me to go for medical checkup after some days after using the herbal cure, I was free from the deadly disease, he only asked me to post the testimony through the whole world, faithfully am doing it now, please brothers and sisters, he is great, I owe him in my life. if you are having a similar problems just email him on () . simply whatsapp him on:. He can also cure disease like Cancer, Diabeties, Herpes, Hepatitis B, Etc.	No action required
14.	Dr Rimi Shah	ViiV Healthcare	Dear Yvonne and members of the Writing Group I am writing on behalf of ViiV healthcare who welcome the updated draft BHIVA pregnancy guidelines 2018 for prevention of MCT. Thank you for the opportunity to comment on the draft The guidelines are both practical and deliverable, and encompass many of the issues faced by both pregnant HIV+women, and their HCPs, within a multidisciplinary team. We particularly commend the inclusion of the comprehensive sections on the psychosocial care of HIV+women during and after delivery, highlighting the importance of holistic MDT care; the safety data of newer drugs including dolutegravir, and the recommendations by the Writing Group, for lifelong treatment for women commencing ARVs in pregnancy, improving long term prognosis. We wished also to comment on the following: With reference to Section 6.3.1, with regard to Writing group 's recommendation to start either Tenofovir disoproxil fumarate or Abacavir as recommended in the BHIVA treatment guidelines. We commend the balanced information and discussion on use of TFF/FTC in pregnancy. We note that	ABC/3TC is one of the recommended backbones for HIV in

			further information on use of Abacavir/lamivudine was not included. The Writing Group may therefore wish to consider adding for further information, that Abacavir/ Lamivudine is an acceptable alternative NRTI component for non-pregnant adults with baseline viral loads <100,000 copies/ml (other than in combination with dolutegravir, when abacavir/ lamivudine can be initiated, regardless of viral load). It offers the advantage of once-daily dosing and is well tolerated in pregnancy2. Testing for the HLA-B*5701 allele should be performed and documented as negative before starting abacavir, and women should be educated about symptoms of hypersensitivity reactions3. With reference to Section 6.4.3- use of integrase inhibitors in pregnancy: As discussed in your paragraph, increasing data on the APR is being collated with the wider use of dolutegravir, and on elvitegravir. The draft guidelines in this section, also refer to data from the Botswana cohort which suggest similar risks of adverse pregnancy outcomes (preterm/very preterm delivery, small/very small for gestational age, stillbirth, neonatal death, or combinations of these outcomes) of women commencing dolutegravir ART compared to efavirenz-based ART in pregnancy. However, for your information, we believe the reference cited 4 (ref 20 in your guidelines - Zash et al JAMA Paedr 2017), may in fact refer to an earlier paper where dolutegravir was not included, and the study that this data refers to, was presented at a later date at IAS 2017 5) With reference to section 6.4.3 pharmacokinetics in use of integrase inhibitors: We note that Writing Group's recommendations for insufficient data to recommend use of elvitegravir/ cobicistat in pregnancy, due to reduced drug exposure and higher clearance of elvitegravir and cobicistat in the third trimester, compared to the post-partum period, from the IMPAACT P1026s study8, the levels of which were found to be significantly lower than that required for virologic suppression. Further data within the draft guidelines, refer to adequate trough levels maintained with use of raltegravir 400mg bd, in the third trimester9 with insufficient data on the pharmacokinetics of 1200mg od Raltegravir, leading to the Writing Group's recommendation of continued use of Raltegravir 400mg bd, until further data available. We suggest that the Writing Committee may therefore additionally, wish to include further results from the ongoing IMPACT 1026 trial, where Maternal dolutegravir pharmacokinetics were also assessed. These showed that the calculated dolutegravir area under the concentration versus time curve (AUC) was 25–30% lower in the 2nd and 3rd trimesters but this however was not statistically significantly different from the AUC calculated during the postpartum period. The AUC was also numerically similar to non-pregnant adults. Therefore, whilst DTG exposures and trough levels were lower in pregnancy in third trimester vs post-partum, they were still similar to non-pregnant adults, and	pregnancy These data have been superseded This has been added with the reference

			therefore no dose adjustment is required 10 And finally, from the more personal viewpoint as an HCP with an interest in pregnancy, I also wanted to add that the section on postpartum and postnatal management with its holistic approach and discussion of ways to improve retention of care and advice on breastfeeding for those women who wish to explore this, was informative and highly relevant to all HCPs engaged in the care of HIV positive women. Thank you again for the opportunity to comment on the Writing Group's very comprehensive and pragmatic guidelines. Yours sincerely, Rimi Dr Rimi Shah FRCP MBBS and Dr Annemiek DeRuiter FRCP MBBS - on behalf of the UK Medical team at ViiV healthcare References 1. Your Ref 3 in section 6.1.3 2. Shapiro RL, Hughes MD, Ogwu A, et al. Antiretroviral regimens in pregnancy and breast-feeding in Botswana. N Engl J Med. 2010;362(24):2282-2294. Available at http://www.ncbi.nlm.nih.gov/pubmed/20554983 3. Ref 7 in section 6.3.1 – BHIVA 2016, BHIVA treatment guidelines for the treatment of HIV-1 positive adults with Antiretroviral therapy. 2016 interim update 4. Zash R, Jacobson DL, Diseko M et al. Comparative safety of antiretroviral treatment regimens in pregnancy. JAMA Pediatr 2017; 171 : e172222 5. Zash R, Jacobson D, Diseko M, et al. DTG/TDF/FTC started in pregnancy is as safe as EFV/TDF/FTC in nationwide birth outcomes surveillance in Botswana. Presented IAS, France, July 23–26, 2017. Oral presentation MOAX0202LB 6. Your reference 52 in section 6.4.3 7. Your references, 47/49/51 in section 6.4.3) 8. Mulligan N, Best B, Capparelli E, Stek A, Barr E, Smith E et al. Dolutegravir pharmacokinetics in HIV- infected pregnant and postpartum women. Conference on Retroviruses and Opportunistic Infections. Boston, MA, USA. 22–26 February 2016 (Abstract 438	

15.	Angelina Namiba	Salamander Trust	Firstly, thank you for the opportunity to comment on these key guidelines from a patient/lay perspective. Please note that these are my thoughts rather than organizational ones. The layout is much easier to navigate and the changes as well as use of positive language overall is very welcome. Eg where your refer to women living with HIV Vertical transmission. 2.1 Really welcome the inclusion of the assessment of antenatal and postnatal depression in accordance to NICE guidelines. 4.1.2 I really like the section on explaining the process of inpatient care so that women can be supported in informing ward staff explicitly about maintaining confidentiality especially around visitors. 4.1.3 Great to see the section on antenatal MDT includes peer and voluntary sector support. Would it be possible to reword this to - with a STRONG recommendation of peer and voluntary sector support. To highlight the value that peer support eg trained Mentor Mothers, can can have on complementing clinical care. 6.2.2 Women should start ART as soon as they are able to. Like this wording as it seems to take into consideration treatment preparedness & gives a little leeway for women to think about and make informed choice around treatment especially if they are diagnosed early/in good time. 8.2 Clear guidance on mode of delivery 8.3.3 immediate c-section considered if maternal viral load is 50-999 c/ml. Guidance much clearer I think than previous one which was 5-400. 9.4.2 Good to see recognition of the fact that abstaining from breastfeeding can have financial and psychological repercussions for some. And that these women should be supported by MDT. 10. Post natal managemgent of of women. Good to see offer of carbagoline for women not breastfeeding, clearly stated. As anecdotally, some	This has been changed to a strong recommendation

			women encountered in workshops for women living with HIV some women were not made aware that this could be offered. Really good to see the the detailed/thorough recommendation for postnatal management of women.	
16.	Rebecca Thomson-Glover	East Cheshire NHS Trust	Thank you for your work in updating the guidelines. Comments: 6.4.1 NRTIs in pregnancy: ?typo error? in 2nd to last paragraph in pharmacokinetics paragraph should read TAF instead of TDF. Appendix 5 : advice on breastfeeding baby - first page (type missing from safe triangle - happy tums) other comments: would it be useful to have a list of agents that do/don't cross the placenta? No specific mention of LARCs in the post natal contraception section - given trying to improve the uptake of LARC - worth mentioning? plus signposting to fsrh website	This has been corrected Appendix 5: This has been reformatted Beyond the scope of the guidelines – we now link to BHIVA SRH Guidelines
17.	Helen Mactier	British Association of Perinatal Medicine	The British Association of Perinatal Medicine applauds this clearly written and clinically useful update to the existing BHIVA guideline for management of HIV infection in pregnancy. Please advise when the update goes live, and I shall ensure that we tweet the news to our members, and have a link on our website. Thank you Helen Mactier	To be actioned
18.	Dr Margaret Kingston	Northern Integrated Contraception, Sexual Health & HIV Service	Dear BHIVA, I am collating a response to these from the Manchester HIV team. There are some significant changes and the guideline is well reasoned and written in my view. However there are significant pragmatic issues we need to consider as a busy team working in a very large maternity unit in order to avoid the wrong thing inadvertently being done. Guidelines need to be evidence based of course, but they also need to be able to be safely implemented. However, you have given us too little time to prepare the response as the date of receipt of your email to 19th Feb when you wish to receive the response is 3 working weeks, one of which is a school holiday when many of us are away; so effectively 2 weeks. This is not enough nor is it consistent with the BHIVA guideline production manual section 3.7.2 which states that members have a month to comment. We will therefore have a response to you by Friday 23rd Feb which is 4 working weeks from response of your email and I think it is reasonable to expect you to accept our response.	Comments have been accepted

			Best wishes Margaret	
19.	Alison Blume	Solent NHS Trust	I wonder if the writing committee could clarify the dose of Raltegravir. Currently the guidelines state "It is recommended that women conceiving on a cART regimen should continue this" and "No routine dose alterations are recommended for ARVs during pregnancy if used at adult licensed doses" However the section on Raltegravir states "Pharmacokinetics of the raltegravir 1200mg once daily formulation have not yet been studied in pregnancy and it is recommended that the 400mg BD dose is used until further information is available." Could the writing committee make it clearer as to whether women conceiving on Raltegravir 1200mg OD should be switched to BD dosing? Many thanks.	Added to 6.1.1 in summary and in main section PK section clarifies this
20.	Andrew Hill	University of Liverpool	This review paper on DTG in pregnancy is in review - it should be published within the next 4-6 weeks. The overall results could help to support the use of DTG in pregnant women. Andrew Hill, Polly Clayden, Claire Thorne, Rachel Christie, Rebecca Zash. Safety and pharmacokinetics of dolutegravir in pregnant women – a systematic review. J Virus Erad 2018; **3**.	Reference has been included
21.	Laura Waters	Mortimer Market Centre, CNWL	Thank you to the committee for such a great piece of work! Well done! The clearer guidance regarding infant PEP is particularly welcomed. Comments: 1. May just be a draft issue but the formatting makes cuts the top off some sentences 2. Section 1.3: is it worth asking RCOG to share a link to the guidelines on their website once finalised? 3. Section 1.4: suggest a bit more clarity around 'conferring regularly' e.g. via BHIVA guidelines subcommittee? Annual email/phone reviews of data? 4. Recommendations page: Recommendation 4.1 sounds slightly woolly due to the 'composition will vary' bit….suggest remove that and leave the composition bit for the text? 5. Recommendation page: recommendation 5.2.4 advises following BHIVA monitoring GL - this means if a woman with a CD4 >350 starts ART in pregnancy the CD4 won't be checked again which is not	2. Will check if possible 3. Will be organised 4. Done and within summary points 5. This has been addressed

			consistent with 5.2.3 (i.e baseline + delivery) so need harmonizing? 6. Section 5.1, paragraph 3: I think the last sentence needs qualifying wrt suppressive ART. For ref 13 the paper, as far as I can see, does not correlated cervical HIV RNA with plasma? Ref 14 seems to be a study in untreated women? My concern is the trials are not necessarily applicable to virally suppressed women – you cover this issue well in section 5.1.3 so suggest a qualifying line added to para 3 also. 7. Section 6.1 and recommendation 6.1.1: since PI monotherapy is actively not recommended by BHIVA ART guidelines I hope this qualification would be obvious – though still worth highlighting. I think the issue that needs to be addressed specifically is related to dual ART. Since, to my knowledge, nearly all data related to PMTCT is for triple ART I wonder if you should go a step further and say that all pregnant women should be on a triple ART regimen and unless there are clear, MDT-agreed reasons, dual ART is not recommended? I accept it's a bit of an evidence-free zone! 8. Section 6.1, para 2: related to stopping ART during hyperemesis – suggest add something about repeating a R test if this is an NNRTI based regimen? 9. Page 34, EFV paragraph: this is an important statement and suggest EFV is specified in the recommendation? E.g It is recommended that women conceiving on a cART regimen should continue this, including EFV-based ART' 10. Recommendation 6.3.1: since BHIVA ART GL also recommend TAF so you need to state here that TAF not preferred? In the PK section on page 39 you recommend against TAF so I think this should be included in the overall recommendations. 11. Section 6.4, para 2: is 'falls pregnant' still accepted terminology? Sounds a bit outdated but maybe I'm being (even more than usually) pedantic? 12. Page 389 para 2: I think the last sentence referring to twice to TDF should be referring to TAF? 13. Section 6.4.3: Similar to TAF I think if RAL 1200 OD not recommended this should also be a standalone recommendation? 14. Page 40, last paragraph: The PK section for PI is quite wordy – suggest shortening +/- tabulating. 15. Same section: similar to TAF and RAL OD, does avoiding COBI need a specific recommendation? I think the point about EVG concentrations should be in the INI PK section? And sorry of I've missed it but I think you should reference the 'tail' data of RTV vs COBI with ATV and DRV (Boffito) as may help clinicians/patients make decisions re continueing COBI vs switch to RTV? 16. Page 42: PTD discussion is long, again suggest shortening +/- tabulating for ease of reading 17. Recommendation 6.5.2: suggest this explicitly dates RAL 400mg BD	6. This has been actioned 7. This has been addressed, extra line added 8. This has been added back in and addressed 9. Line has been added 10. This has been clarified 11. We agree and have changed this 12. This is correct, it has now been changed 13. Line has been added 14. Has been shortened where possible (difficult to do so) 15. We have made a comment about COBI already – do not recommend starting and recommend switching off 16. We have tried this in various forms but it is

			18. Section 6.5, final paragraph: is POCT (bearing in mind most are still 3rd generation) sufficient in a woman at ongoing risk? Should a plasma 4th generation test also be recommended if recent risk? 19. Section 7.1: I think this would benefit form a short discussion about TAF e.g. if TDF contra- indicated does the balance of benefit wrt HBV alter the balance for using TAF in pregnancy for HIV/HBV co-infected women? 20. Page 55: since this references the Green Book I think worth stating that and clarifying that the following recommendation was correct at time of writing but clinicians should check the Green Book for most up to date recommendations. 21. Section 7.2 para 3: clarify that coinfection refers to HIV coinfection (pretty obvious I know but since it follows directly on from HBV section then worth clarifying? 22. Recommendation 7.2.3: should it not be 'pregnant women' rather than 'mothers'? Not all pregnant women are mothers, nor are all mothers pregnant…. Also the statement to discontinue both therapies immediately is confusing since different DAA regimens have different numbers of components so suggest this is changes to 'discontinue all components of HCV therapy immediately'. Situation is admittedly unlikely but I think you should also advise HCV resistance testing in this situation? 23. Section 9.2.1: do infants requiring PCPP need G6PD testing? 24. Section 9.4: I have mixed feelings about this section while I recognise the importance of the mother's views, culture, stigma and ensuring engagement with services, I do think that choosing low risk breastfeeding when there is a zero risk alternative could be considered an unacceptable risk. You don't recommend breast feeding, granted, and I agree that suppressed women who choose to breastfeed should be supported to do so but I think you can make the recommendations more explicit e.g. "we recommend formula feeding….etc" and "we do not recommend breastfeeding but….." 25. Recommendation 10.4.1: I completely agree but understand, in England at least, this is not commissioned? Do the panel have any practical advice if patients or clinicians experience barriers to free provision? A short paragraph that covers this would be welcomed. 26. And that's it! I hope at least some of these comments/suggestions will be helpful and well done again to you all!	hard to simplify as data are complex 17. This has been actioned 18. We agree and have added to the text 19. This has been commented upon already 20. Line has been added 21. Had changed already 22. This has been addressed 23. Not routinely recommended unless Septrin allergy 24. We have added our recommendation to 9.4.1 so it is clearer 25. We have added text suggested by NAT
22.	Dr. Michael Evangeli	Royal Holloway University of London	I am a clinical psychologist, so my comments refer to section 4.1. 1. The draft guidelines state that "Data from the UK-based ASTRA study reveal that the prevalence of depression among women living with HIV is nearly 30% [2]", and "According to a systematic review of HIV and perinatal mental health, the prevalence of postnatal depression (PND) among women living with HIV in high-income settings is reported to be between 30 and 53% [5]." If these figures are based	1. The text has been changed

			on how patients respond to self-report measures this is NOT a reliable or valid basis for a diagnosis of depression. Self-report always overestimates diagnosed mental health problems. More accurately, you can report the prevalence of those with depressive symptoms. 2. I supervised two doctoral clinical psychology students theses on bonding in HIV+ women (one in women diagnosed in pregnancy from which the Willcocks article is derived; the other in perinatally infected women - Evangeli, M., Millner, F., Foster, C., Jungmann, E., & Frize, G. (2015). 'I've done my job, so my daughter doesn't have to be like me': The experience of becoming a mother with perinatally acquired HIV. AIDS Impact Conference, Amsterdam, Netherlands. July 2015. NB This presentation reports findings from an published thesis: Millner, F. (2015). The experience of being a mother with perinatally acquired HIV. DClinPsy Thesis. Royal Holloway, University of London. https://pure.royalholloway.ac.uk/portal/en/publications/the-experience-of-being-a-mother-with- perinatally-acquired-human-immunodeficiency-virus-phiv(4235e1d6-e797-4eae-b2da- 30042fe6c8e8).html A number of findings from these studies would be helpful to include in section 4.1: From these studies: a. bonding difficulties were reported (at times) in both studies, often associated with the uncertainty of the infant testing process and also with breastfeeding restrictions. I would suggest mentioning bonding difficulties as one factor that is plausibly associated with depression in either population (behaviourally or perinatally infected mothers). Managing bonding difficulties, promoting behaviours to enhance bonding and normalising these may be important for mother and child. Of interest, in the Willcocks study, once the child testing process had finished, mothers described a developing special bond with their child (i.e., sharing a secret and having gone through challenges together) b. anxiety about transmission of HIV to the unborn and newborn child, particularly at the time when the pregnancy was discovered (suggesting the importance of timely information provision to the mother) in both studies. c. the role of faith in adjustment (in the Willcocks study in particular). I did not see faith mentioned, and it is highly relevant to a significant proportion of the population. d. feelings of guilt towards the child (both studies) e. feelings of shame (both studies) f. a high frequency of thoughts about termination initially (both studies) g. feelings of inadequacy due to breastfeeding restrictions (particularly in Willcocks). In the Millner study alone: a. many mothers with PHIV thought that their HIV had made them infertile, hence feeling shocked on	2. This is beyond the scope of the guidelines

			discovering their pregnancy (which was usually unplanned). b. fear of abandonment by partner for being pregnant and for having HIV (many had not disclosed up to that point). NB in both studies, many relationships ended during pregnancy. c. fear of rejection by others due to being pregnant whilst knowing that they were HIV+. d. many mothers lacked support due to not having disclosed their status as well as having lost their mothers (to AIDS) previously. Grief support for this population could be important. e. the benefits of a strong continuum of care was stressed by mothers. More generally, the emphasis of the guidelines if very focused on the mother, versus both the mother and her family and child.	
23.	kirsty abu-rajab	nhs forth valley	There is very little info on multiple pregnancies. Would it be worthwhile including some info/ recommending that people speak to others with more experience. Prob easier in London than in Scotland? thanks	Data on multiple pregnancies are up to date
24.	Liat Sarner	Barts Health NHS Trust	Dear Writing group Thank you for producing such clearly written guidelines. The breast feeding section and patient related appendixes are particularly helpful as is the inclusion of the focus on mental health. I have the following suggestions: 1. Auditable outcome 2: Proportion of women who require cart for their own health starting art within 2 weeks of diagnosis: Should this be reworded to define "cart for their own health" by using CD4 parameters given all women who are diagnosed require cart for their own health and should be on life long art. Suggest CD4 < 200 or < 350? Auditable outcome 4 : states women with VL > 30000 not requiring ART for themselves should have started temporary CART by 16 weeks gestation. Given that the guideline support life long ART should the term "temporary cart" be removed and the sentence reworded to state: All women with viral load > 30,000 should have started cart by 16 weeks gestation 2. Perhaps adapt auditable outcome 14 and add all women should have a documented discussion about intimate partner violence at booking 3. In table re neonatal prophylaxis add baby born > 34 weeks gestation to the very low risk table 4. There is no mention of management of HIV-2 infected pregnant women but it is mentioned in the neonatal section. Please can a line be added perhaps referencing the adult guidelines for	1. This has been addressed 2. This is important but not added as an auditable outcome 3. This has been addressed 4. Section has been added back in

			management of HIV-2 or suggest use of INI or PI-? bd DRV for newly diagnosed women or any modification required for those already on therapy? 5. No mention of OI prophylaxis or treatment of OIs in pregnancy-? Reference adult OI guidelines where there is a pregnancy section? In my experience this is relevant for women presenting pregnant who have been LTFU or those getting pregnant soon after late diagnosis.	5. OI prophylaxis or treatment of OIs in pregnancy is beyond the scope of this guideline
25.	Thanyawee Puthanakit		Reference 92 on page 50 could be updated to cite the published paper and also to say that 154 pregnant women receiving raltegravir- as part of 4-drug regimen. Thanyawee Puthanakit, Nattawan Thepnarong, Surasith Chaithongwongwatthana et al. Intensification of antiretroviral treatment with raltegravir for pregnant women living with HIV at high risk of vertical transmission. J Virus Erad 2018; **3**: 000–000.	Reference has been updated
26.	Anna Goodman	British Infection Association	We fully support this helpful new document and are pleased to see representative from the BIA on the author list. Thank you.	
27.	Sarah Mensforth	Coventry and Warwickshire Partnership Trust	A really comprehensive and easy to read document. The information in the Appendix regarding breastfeeding and blood tests is great and will be very patient friendly. I have a few very minor comments below - Pg 32, Table 6.1 the first and second left column boxes referring to Congenital malformation rates - the wording is slightly difficult to understand and might need rewording, if you get lots of similar comments. Pg 39, 6.4.1 - penultimate paragraph: "Tenofovir alafenamide (TAF) is a newer version of tenofovir-DF and whilst there are limited data on the safety and pharmacokinetics of TDF; no signals for concern with regard to birth defect have been seen [36]. The Writing Group does not recommend its routine use in pregnancy until further data are available. All women who conceive on TDF should have a discussion regarding this and consideration should be given to switching women who conceive on TDF if necessary to an alternative NRTI regimen." I think this should be TAF in the last sentence Pg 56, 7.1.1 – 4th paragraph. Referring to the Green Book, use of HBVIg is also recommended if the mother is HBV sAg positive with unknown HBV e markers. If the current level of detail is kept, it may be worthwhile including this.	Table 6.1 has been removed and section rewritten P39. This has been changed P56. This has been addressed

			Pg 98, Appendix 5 – safer triangle The text for "happy tums" does not fit in the box	P98. This has been reformatted
28.	Anna Goodman	Guy's and St Thomas'	Screening for trisomy- the document states: The most effective screening is with the combined test at 11 + 0 to 13 + 6 weeks' gestation. However, new fetal DNA Non invasive prenatal diagnosis/testing is clearly more effective just not yet widely available on the NHS. Given the benefits of such a test in terms of reducing the need for invasive testing, should we not be supporting such testing on the NHS for those with HIV? Thanks	This has been added
29.	Suvaporn Anugulruengkitt	King Chulalongkorn Memorial Hospital, Bangkok	Regarding combination therapy for neonatal prophylaxis. In Thailand, high-risk infants received ZDV (4 mg/kg) and 3TC (2 mg/kg) twice daily, plus NVP (4 mg/kg/dose) once daily, for 6 weeks. We evaluated the nevirapine concentrations and safety of this combination regimen by a prospective cohort study of 200 non-breastfed HIV-exposed infants (100 low-risk and 100 high-risk infants). All infants maintained NVP concentrations above the proposed prophylactic target threshold of 100 ng/mL during the first 4 weeks. Administration of 4 mg/kg of NVP from birth provided adequate NVP concentrations for prophylaxis during the first 4 weeks of life and did not increase hematological and liver toxicity compared to low-risk infants who received 4-week ZDV. Preliminary reports were presented as the poster presentation at CROI 2017 (http://www.croiconference.org/sessions/safety- 6-week-triple-antiretroviral-prophylaxis-high-risk-hiv-exposed-infants). The manuscript is in preparation.	We do not recommend 6 weeks of PEP in infants therefore not added to text
30.	Susan Bewley	Kings College London	Background Thank you for the opportunity to comment on the BHIVA guidelines. The views expressed below are my own. The detailed content is not within my active area of specialism, although I did provide obstetric care for women living with HIV for many years up until 2011, but I am experienced in developing guidelines based on the best available evidence, so my critique is largely methodological. Declaration of interests I was paid to chair a standing committee for NICE 2013-17. I have received fees from the World Health Organization for research and my involvement as a Guideline Development Group member in the 2017 Consolidated Guideline on Sexual and Reproductive Health and Human Rights of women living with HIV http://www.who.int/reproductivehealth/publications/gender_rights/srhr-women- hiv/en/. I was the unpaid chair of the 2017 BMJ Magic-App Guideline Development Panel regarding choice of combined anti-retroviral during pregnancy. Other declarations of interest can be found at 'whopaysthisdoctor', in publications including the BMJ and in NICE documents. Response	All concerns were forwarded to the BHIVA Guidelines Subcommittee All Declarations of interest are available on the guidelines website. We are revising our DOI policy in line with recommendations following our NICE re accreditation in 2018

			My major concerns about the guidelines relate to process and methodological flaws, a lack of transparency, and an inadequate exploration of best available evidence: 1. The composition of the committee There is inadequate lay representation which should be several patients with relevant experience and expertise. 2. Committee chair –conflicted roles. The chair of the writing committee is a member of BHIVA Executive committee. This does not exclude independence of thought, but close personal relationships can create situations of 'group-think' in which challenge may be impossible. 3. Lack of transparency about interests (personal and financial). Transparency enhances a guideline's credibility. I have been unable to find the declarations of interest of committee members as determined by BHIVAs own guidance, http://www.bhiva.org/GuidelineDevelopmentManual.aspx and have had no answer to my request about them. It is important that these are explored. If these interests are not outlined, it's not possible to see where individuals might have links with commercial interests and whether they should have recused for all or parts of the discussion. 4. Prior mindset and potential bias. BHIVA may have had a biased committee, or chair, from the outset. BHIVA has publically disagreed with the recommendations based on two BMJ Open systematic reviews and published by the BMJ after intensive peer review. It is unclear who wrote, produced and approved the press release http://www.bhiva.org/BHIVA-response-to- BMJ-article.aspx written within 10 days of publication of the BMJ recommendations. It seems extraordinary that the full evidence was read, understood, digested and discussed widely with all appropriate colleagues in such a short time before producing the press release. Thus it appears that BHIVAs mind was made up before integrating the new work. Although the chair of the writing committee wrote a very late "rapid response" to the BMJ (which will be answered shortly) it appears to be along the same lines as the press release and has ignored the answers already given to the PROMISE triallists. Whether the anonymous press release was written by the chairwoman of the pregnancy guidelines or a group of clinicians, this is a serious problem. Her position would be untenable as demonstrable prior bias compromises the whole committee's work. BHIVA would have to reconsider the whole guideline as there could be no confidence in the process. 5. Systematic reviews and bias. It is worrying that the consultation document does not refer to the two BMJ Open systematic reviews which should have come up on the search (appendix	There were 2 lay representatives, in line with NICE recommendations This is a valid point and will be considered in future guidelines See above In future guideline chairs will have no conflicts, and all conflicts by others will be declared This section has been independently reviewed and completely rewritten including reference to PROMISE and the relevant systemic reviews See above

			PICO 3), and only refers to the guideline recommendation. The guidelines should not be released without full analysis of all three papers • The BMJ Rapid Recommendation paper http://www.bmj.com/content/358/bmj.j3961 was based on two systematic reviews that do not appear within the pregnancy guideline references (and should): • BMJ Open Systematic Review on Women's Values and preferences http://bmjopen.bmj.com/content/7/9/e019023 • BMJ Open Systematic Review on effects of various combination ARTs http://bmjopen.bmj.com/content/7/9/e019022 Unfortunately, as the two BMJ Open SRs are not referenced, this gives the impression that the writing committee simply haven't read them, and are thus unable to take them properly into account despite finding themselves able to disagree with the subsequent BMJ guidance. This makes BHIVA look prejudiced (pre-judging). The whole point of a systematic review is to have a prespecified protocol to eliminate bias. The BMJ panel started with a 'values and preferences' systematic review involving women living with HIV, and the guideline also involved three women living with HIV. The processes were excellent. Good decision making tools were provided for women patients also. So, when BHIVA argues against the BMJ recommendations but fails to give an adequate explanation as to what exactly is wrong with their underlying methods, BHIVA looks foolish.	See above
			6. Unsustainable conclusions Thus, the BHIVA guideline reads as if: 'we don't like the result, so we are going to cherry-pick what we do like'. For example it states that *"Three previous systematic reviews [16-18] reported no increase of birth adverse events or safety events (and no increased risk of congenital anomalies) in infants exposed to tenofovir- compared to non- tenofovircontaining regimens in HIV-exposed infants, although data remain limited and studies evaluating neonatal mortality, infant anthropometry and bone growth are required. WHO used these systematic reviews to inform their guidelines on HIV and pregnancy, which include the use of tenofovir-containing regimens [27]."* It is not adequate to say we prefer such and such an SR, the data from which has been incorporated in a later high-quality review. It's not a question of counting 3 reviews this way vs. 1 review that. There has to be a proper determination of quality (which BHIVA has not done). BHIVA has failed to recognise methodological quality which thus supercedes the previous work. At BMJ peer review the WHO commented that the methodology was faultless. WHO has not taken the BHIVA stance. Why not?	We hope these concerns have been addressed by the re write of this section and reference to these and other papers reviewed and graded by the writing group All members of the writing group undertook training in grade methodology prior to working on this guideline

			Additionally BHIVA states "*A British Medical Journal (BMJ) systematic review 'strongly recommended' that pregnant women living with HIV should not be treated with the combination tenofovir/ emtricitabine/ lopinavir/ ritonavir due to higher rates of early neonatal death reported in the PROMISE randomised clinical trial [26]. The Writing Group disagrees with this recommendation".* This is completely inadequate. How can the writing group 'disagree' when they haven't examined the data or taken it into account? There has been some 'pushback' on this work from the outset. I don't understand the reasons, but the methods are excellent and transparent and aligned with highest standards (as picked up by the BMJ peer reviewers). 7. <u>Attitudes to women:</u> Through the text there is inconsistent terminology. A pregnant woman is not 'a mother' before she has her child. I notice that the principle of shared decision making with an adult woman is not highlighted. It appears that vertical transmission (of course an issue for pregnant women, but not the only issue) is given pre-eminence above everything else, particularly the mother's health, and the baby's health. A minor point is that p107 shows rather scary pictures of injections. It's not clear why this is so dramatic, and it risks putting women off, rather than taking part in proper shared decision making. 8. <u>The precautionary principle</u> HIV clinicians have a moral and legal duty to explicitly discuss the benefits and harms of each prescription with their patients, so that they can decide what is best for themselves. In this case, failing to mention the possibility that TDF and/or FTC may lead to spontaneous abortion and neonatal death breaches these duties. BHIVA have not given a solid basis to the recommendation on *"Prescribing: all women are recommended to start on treatment and remain on it lifelong",* given that many women will subsequently become pregnant, and the implications for pregnancy should be considered from the point of diagnosis. The writing group has failed in its duty to consider the full implications of cART and pregnancy. BHIVA and other HIV professional societies should have previous teratogenic and other public health disasters at the forefront of their mind when they consider whether or not to adopt the precautionary principle in their recommendations for pregnant women. 9. <u>Promise to revise</u> Apparently "the guidelines will be next fully updated and revised in 2023. The Writing Group will, however, continue to confer regularly to consider new information from high-quality studies." This is somewhat disingenuous given that BHIVA failed to properly consider the new information from 2017. <u>Summary</u> BHIVA failed to recognise important methodologically sound work, and made an immediate, anonymous response, which 'cherry-picked' data. This was then picked up very quickly by pharma-funded activist sites. The failure to incorporate the 2017 BMJ Open systematic reviews is a fatal	The terminology is now consistent and the guideline reflects the principle of shared decision making with informed consent. The graphic referred to has been changed National and international guidelines now recommend universal HIV treatment for all adult patients regardless of CD4 count. We recommend all clinicians contribute to the antiretroviral pregnancy register to ensure no mother or baby is exposed to unnecessary risk We aim to revise the guideline in 2021 but will issue amended guidance in the meantime if relevant new data become available

			flaw. Whilst I accept that all current knowledge is contingent, and might change with new data, the 'best available evidence' is now being presented as 'controversial', BHIVA obfuscates and has made unsustainable recommendations. Whose interests does that suit? Certainly not pregnant women worldwide. Future commentators might think it is more controversial for the prescribers of drugs to ignore a worry about cART in pregnancy.	BHIVA did produce a prompt statement on dolutegravir in pregnancy in 2018, We value criticism and challenge of our process and guidance. It helps us reflect and produce better guidance and we sincerely thank you for your contribution and help A statement about choice has been added to the postnatal continuation of cART section
31.	Regina Da Silva	Independent Researcher and Consultant	As senior researcher and international health consultant, public defender working and studying in the field of maternal and neonatal health for 29 years with focus on breastfeeding in the HIV and AIDS context for high, middle, low income countries and global level programs, unfortunately I do not recommend the BHIVA guidelines for the management of HIV infection in pregnant women 2018 due to several reasons, as follow: 1) The guidelines need further assessment and more careful review before be available for any public online review. In other words, the writing group members need further external assessment with more updated scientific evidences to review line by line of that guidelines presented already for public consultancy. Probable, it would take at least three months for a full time reviser before be available for any public review. Apart the lack of further scientific evidences, even with poor attempt to adopt GRADE evidence grading system by the guidelines, in terms of powder infant formula (PIF) recommendation and BHIVA approach on HIV and breastfeeding, there is not any mention to "The Infant Formula and Follow-on Formula (England) Regulation 2007" and safe preparation/storage of PIF; 2) The title of the guidelines is not appropriated, when it is mentioned 'management of HIV infection in pregnant women', but in fact is mentioned recommendations on the postpartum period, including HIV and breastfeeding; 3) There are several sections, e.g. 4.4 related to perinatal mental health assessment with lack of	1) No further action taken 2) Title has been changed 3) We believe in expanding the

			holistic and humanized assistance, when recommending, for instance, 4-6 weeks assessment of postnatal postpartum as the actual NICE protocol; 4) The appendix 5 / Information on infant feeding from St. Mary's Family Clinic, is un outdated material with issues related to the Code compliance. It is an educational resource to the general population of women living with HIV without any reference, but just indication as 'Helplines' of four groups that it seems that represent the friend circle of the author that certainly will support PIF and bottle feed, rather than group of professionals that represent more strong commitment with issues related to HIV and breastfeeding in England. To sum up, I strong recommend for the writing group to seek external assessment, before the guidelines be available for public consultancy again. For instance, the writing group could have the support from the follow groups: 1) For GRADE system – World Health Organization team/ Geneva; 2) For issues related to "The Infant Formula and Follow-on Formula (England) Regulation 2007" and safe preparation/storage of PIF – The Baby Milk Action UK; 3) Most updated evidences on breastfeeding and HIV according to actual global policy for countries – BLCLC Counselors in England and Association of Breastfeeding Medicine / ABM from USA.	psychosocial section and prioritising it in the guideline that we are advocating a holistic approach
32.	Alice Welbourn	Salamander Trust	Many thanks for the opportunity to comment on these new pregnancy guidelines. They are very comprehensive and it is great to see so many advances in science being translated into new or revised recommendations. I would like to make the following comments in a spirit of collaboration, as a critical friend. I have gone through the whole document and commented with sticky notes. I am planning to send this in also. a) Additional new articles. It is really interesting to read this in light of the parallel process in which I am currently involved with colleagues, of supporting country implementation of the new WHO Guideline on the SRH&R of women living with HIV. There is inevitably a lot in there which is directly relevant to these guidelines. It would be great if the new WHO Guidelines could be cited somewhere in this document. (http://apps.who.int/iris/bitstream/10665/254885/1/9789241549998- eng.pdf?ua=1) We have also just co-published with UN Women and other partners a global treatment access review for women living with HIV, with a paper published on it in the Harvard Journal of Health and Human Rights (https://cdn2.sph.harvard.edu/wp-content/uploads/sites/125/2017/12/Orza.pdf). This shows how much violence can feature at every stage for women living with HIV, including of course in pregnancy. It would be great if you might consider reviewing these publications also, since they too	a) No action taken – this is UK guideline Reference has been added

			seem very relevant to your new Guidelines. b) Overall, the general tone of the Guidelines still seems to be focused primarily on disease prevention rather than primarily on the safety and well-being of each individual woman as she embarks on this special journey in her life. As the new WHO Guideline highlights, it has taken a women-centred, rights-based approach in the Guideline. It would be wonderful if the Writing Group here might consider shifting the focus of these new UK pregnancy guidelines to echo the WHO Guidelines - ie to place women's intrinsic rights to their SRH front and centre of the document, on the principle that if a woman is happy, healthy and safe, she is then best able to look after her baby to her best ability. I have made some suggestions throughout the text to this effect. This would not be a huge piece of work at all and could make the whole document much more woman-focused and women-friendly :-) c) Language. We appreciate the steps taken to improve the language throughout. However there are still some sections which retain old language, including "MTCT, failure, default, elimination" as well as use of the words "infect' and "infection", neonates and mothers in many places. By contrast, in other places, the word "infect" has been replaced by "acquire" or "transmit" and "mother and neonate" has been replaced with woman and newborn or infant. In both cases, we would like to propose that the document is consistent in its use of language throughout and that the latter examples replace the former examples, since they are more neutral and less emotive. (See also UNAIDS Terminology Guide 2015, Dilmitis et al JIAS 2012 and UNAIDS webinar: http://salamandertrust.net/wp- content/uploads/2015/03/ALIVHE_Webinar_1_-_The_politics_of_Language_-_All_Slides.pdf) d) Questions around the BMJ article on ART. Here you state: "although data remain limited and studies evaluating neonatal mortality, infant anthropometry and bone growth are required." I think this phrase is really important to point out. My concern about tenofovir is that it is still such a new drug and that Gilead itself points out the concerns about bone density. Looking at the long term prospects for children and women alike, if a drug is potentially going to have long term bone density issues, surely this should be a major red flag. In pregnancy especially, surely we should all be at pains to exercise the Precautionary Principle, preferring to use drugs that have a long term track record of being OK, rather than using newer drugs for which we don't yet have that track record ? If it did turn out that tenofovir had long term side effects on bone density, for the woman and/or the child, then what? Some have argued that taking 2 pills a day instead of one can raise violence concerns for women - but as you rightly said earlier, women - with the right support - can find a way round this by saying they are eg vitamin pills etc. If a woman is going to have a problem with pill taking, she will have it whether it's one pill or two, not suddenly because it's two pills a day. It should also be clear that this should be the woman's decision, rather than have it made for her. In addition, Tenofovir is not recommended when breastfeeding. So does this mean the woman would	b) Now added as first sentence in intro: A key goal of managing HIV in pregnancy and postpartum is to optimise a woman's health in her own right. c and d) Have been addressed

			have to change her tx if she decides to breastfeed? The argument on the BMJ site by EGPAF staff appears to raise concerns about resource mobilisation and simplicity of streamlining tx. However, it seems unacceptable that one should ever make a decision for pregnant women based on this - I assume this is not an issue in the UK. (EGPAF also have considerable funding from GILEAD, which they don't disclose in their response.) In addition, if WHO feels challenged by the BMJ recommendations, why has it not responded to them? This leaves us assuming that WHO does not wish to challenge them - which adds further confusion. e) Questions around whether or not to take cART at all and whether or not to breastfeed. The new WHO Guideline emphasises at all time the key principles of voluntary, confidential, informed non- judgemental choice and the need to support women whatever decision they make. This is important of course to build trust as much as her right. It would be great please if you could flag this up regularly throughout the document, so that it is always noticed at any stage in the guideline. In addition, the 4M Network of 'Mentor Mothers' have provided thoughts which echo this stance. f) Connected to this key issue of trust in healthcare providers, is the ongoing concern about potential intimate partner violence or violence from in-laws, community, workplace and other healthcare professionals. It would be great if, each time a woman does not appear to be doing what the MDT 'want' her to do, this question could be flagged up, so there is increased awareness of how important yet hidden this is and how hard it can be for women to talk about. This is addressed in the HHR Journal article and the UN Women report cited above. It would be great if the whole document could perhaps begin with the importance of building trust from the outset (see eg https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5037933/ - despite the language of the title!) and forwarding planning, as fundamental parts of the success of the whole process. g) Also: it would be so great to add in something about sexual pleasure into these guidelines. Pregnancy can be a very positive time for people's sexual relationships and it would be great to flag this up and support women in this, in this document also. I've made some suggestions in my sticky notes on this. h) And lastly, would it be possible to add a couple more women living with HIV to the writing group in future, who have also gone through pregnancy whilst pregnant? Particularly, for instance women who have dealt with migration issues. i) Finally, WHO has just produced a document promoting the key importance of positive experiences of women in relation to childbirth in general. It would be great to reference this document here also: http://www.who.int/mediacentre/news/releases/2018/positive-childbirth-experience/en/ I hope these comments and suggestions are of some use. Thanks again for the opportunity and for all	e) Have added patient choice to post-partum section f) Language changed to reflect this more clearly g) This is beyond the scope of the guidelines h) We agree – this will happen for all new BHIVA guidelines i) Not UK

			your huge efforts.	
33.	Angelina Namiba		Dear Yvonne and Shema Please see comments from 4M Mentor Mothers regarding mainly the infant/breast feeding section. The comments are from a conversation we had on our active WassApp group that was set up after we trained 14 MMs in Manchester in October last year. This conversation follows feedback we shared after some of us attended the recent Breast is Best debate held at the Lewisham hospital on the 31st of January. I have sent the comments via email rather than in the consultation document comments section as it is very much a conversation. However, I thought the writing group would like to see the comments as they relate directly to the guidelines. Happy reading. Angelina x ---------- Forwarded message ---------- Comments relate mainly to the infant feeding section. M: Thoughts are about exclusive feeding I did not know this meant no solid food, it makes sense not to strain the digestive system I fed my babies food before 6 months Papayas avocado banana, was a dispute between my mother in law and aunties and my mother and health visitor neighbour. Clear information helps education their gut was not developed enough and perhaps why all have stomach problems now. The paediatrician said it's ok to give the occasional formula to a breast fed baby of a positive mother as I remember would appreciate clarification on that ? Another positive woman who contracted through breast milk questioned how the arts would affect mental health /brain development of breast fed infants, other positive mothers shared their joy at breast feeding 'it was amazing !' So it has to be an empowered educated choice from mum N: My stance on this is the meeting was very interesting and informative. I believe Breast is Best as it is a natural thing! I came to realise how hard it is for Mothers living with HIV and health professionals to make a decision. There were two very experienced doctors with contrasting believes, one who believed it was the mother's best interest to Brest feed if fully and closely monitored, the other doctor however felt it was not on the best interest of the baby. Then the Audience also had contrasting believes as to whether the BHIVA guidelines should be amended or not. It was intense and very interesting. This is a clear Ethical Dilemma for mums as well as the medical professionals. Like XXX I didn't understand why women who wanted to breast feed were advised to breast feed	

			exclusively for 6 months. Now the doctor explained it and clearly that it's because at six month babies starts Weaning and its the solid food the baby is swallowing that might cause the bruising/sore and risk HIV passed on to baby though breast milk! I am still having a block as to whether the guidelines should be amended or not, still cunfused really confused. Personally I feel as long as there is still that tiny risk I will not advice, which is why I did not Breast feed any of my kids. The Struggle continues! F: Ok can I throw a cat among the pigeons. Breast is best. Yes some of us did not breast feed for many reasons. But now while we are celebrating U=U us this not one iv the steps. ? G: Your point F, sums it up!. Looks like we are preaching water and drinking wine. As I shared my personal experience before, I didn't breastfeed my first baby for the same reasons, but I did breastfeed my second baby exclusively for 6months and both are negative. I think BHIVA guidelines should give this provision and proper guidelines then leave it up to the mother to decide from a well informed standing. A: "well informed non-judgmental voluntary choice - and full support and ongoing care (eg regular checkups) from her healthcare providers, whatever she decides - and whatever might go wrong for her..... " How does that sound?? M: The regular check ups was also an issue having baby tested, getting to clinic. It is a leap of faith from paediatricians/ consultants and mums. Non judgemental is great language I remember a mother battling child protection for the right, another pressure and seeds of self doubt that should not be planted. To be consistent with the rally cry of u=u is important but if a mother wants to formula she shouldnt feel that this is also wrong, it is tricky Some mums really want to breast feed and can't and feel a failure, it's a huge issue even outside the hiv world I talk to a lot of new mums struggling, successful feeding is about being relaxed, confident and calm. This is such an emotive issue and one that I felt right to my core after the meeting. The point at which my diagnosis really hit me was when I was told I couldn't breast feed, I had fed my first two and loved it, it ignited a sense of self worth within me, I was nourishing my children, It is the epitome of motherhood and a beautiful bonding and self affirming experience, I am oils want every mother to experience But if given the choice again I think I would still formula as an hiv positive mum... I have the advice 'if you had 100 bottles and one had poison in would you risk giving your baby any bottle why risk the breast' ringing in my head and know I would have that thought each time the fear of transmission, but who knows with the hormones kicking in love may make me change, I fought to have medication to stop my breast milk, the doctors denied the prescription as 'it would make me feel depressed' I remember shouting if my new born is crying and my milk is flowing and I can't feed her that will make me depressed ! ' I got the meds is there any guidelines about this ? to make a choice what is best for a baby and mums only mums know, we are the only true source from which a decision should be made.Impartial guide lines are so important and have such ripple affects so no pressure Angelina ! I am remembering how I was	F: Added sentence to clarify we cannot apply U=U to breastfeeding yet

			advised to give salt and sugar water to my baby, because in Kenya that solution had saved lives if baby had diarrhoea malnourished and that information had been passed on in away that wasn't accurate but well meaning, I see young mums now go extreme about salt and sugar content of food for 2 year olds, the vaccination debates, in resource rich countries there is so much information and fear about the long term affects of what we give our children, and sometimes the irony of mums fretting over sugar content in a juice and yet ignoring the child who just wants love and attention and giving them an I phone to play with ! Sorry seem to have written a lot gone of track and ranted ! Think this is all bubbling within me because it is so important, and need to respond wisely as setting a precedent x M: Still ruminating, there should be an invitation to all mums to join research when discussing this choice, not all mums can be trail blazers like N and not all consultants are Mavericks, but being part of a scientific study could tip the balance, as it offers non judgemental support, it is an investment in a resource that can help future mums make an informed choice and encourage all health workers and mums. We need more statistics so this whole debate should be a springboard for more research. It's about consent when compared to u=u 2 people making an informed choice to have unprotected sex is very different from feeding a baby that has a choice made for it, as mothers we have that ultimate responsibility, as a village we have a responsibility to support her. A: Hello ladies. Great point of views. I just believe if mothers can breastfeed in Africa without any major supports then it has to be done in the UK. But every mother is different so it has to be a choice. U=U has to be a reality in all cases otherwise it does not make any sense. Yes more researches are needed but worldwide how many mothers have infected their babies by exclusively breastfeeding? If it worked elsewhere then no need to spend 10 years debating about a reality.	
34.	Amanda Williams	London North West University NHS Trust	In general easy to read and clear guidance. specific comments: 5.2.7 As term pregnancy likely to deliver normally from 37 weeks, plan to intensify treatment based on VL at 36 weeks, which involves getting vl test done, getting result back showing VL is detectable, then initiating resistance testing and getting result back and then making changes to intensify treatment, makes it practically challenging to get useful interventions done before delivery. If VL done at 34 weeks then practically easier to get all interventions done and vl suppresses by term delivery. Using vl at 36 weeks to decide mode of delivery is ok. 7.1.13 Perhaps specify 'rapid schedule for immunisation'. Ie within 24 hrs, 4 and 8 weeks in addition to routine hep b vaccinations. 7.2.6 should this read: in all HAV non-immune, HCV co-infected women?	5.2.7 This has been reviewed. Recommendation remains to do final VL at 36/40. If a woman is struggling or there are concerns about adherence, VL will be clinically indicated before 36/40 7.2.6 This has been

			10.4.1 women advised not to breastfeed should be provided with free formula. Agree totally but there is no current mechanism for units to get this done and GP practices can't prescribe formula. There should be an additional statement to say who provides and how and who pays (I can see info on the St Mary's breastfeeding leaflets) St Marys leaflets- great. Suggest they should have the St marys logo on all pages as they only have Bhiva logo. I cannot see any reference to women who refuse to test for hiv in pregnancy, either what should be done to encourage to test or what testing or interventions should take place for a baby born to a mother who has refused to test for hiv. This should be included in my view given that transmissions have occurred in these circumstances and this is the target audience who have the responsibility for carrying out screening.	changed 10.4.1 This has now been addressed, moved to section 9 Leaflets have been changed This is beyond the scope of the guidelines
35.	Adele Torkington	HIV Pharmacy Association	On behalf of the HIV Pharmacist Association we think the guidelines are comprehensive and well structured. Recommendation 7.1.6 consider adding in tenofovir DF to clarify which preparation should be recommended Recommendation 7.1.8 the wording around TDF and TAF is a little ambiguous, it would be preferable to add in "preferred option to be given with tenofovir DF in co-infection" Recommendation 7.2.3 the wording could be misinterpreted to discontinue both HCV and HIV medication, rather than ribavirin and the DAA perhaps. Page 39 2nd paragraph, there is confusion between TAF and TDF. Its states if you conceive on TDF, consider TDF. Figure 9.1 The algorithm is very useful and will be good for prescribers. Appendix 4 the layout is very good and we welcome this simplification for zidovudine. In Duration oral dosing for zidovudine it states monotherapy for 2 weeks, this should specify for very low risk and then 4 weeks for low risk, currently it states combination therapy – 4 weeks.	These comments have been addressed
36.	Erin Williams, Stephanie Maia & Emma Veitch	Infant Feeding Support UK	We enclose some brief notes of feedback from Infant Feeding Support UK with regard to BHIVA's updated guidelines on the management of HIV infection in pregnant women. Infant Feeding Support UK (IFSUK) is a group of parents and scientists who advocate for the communication of safe, unbiased and science-based infant feeding information to parents and carers	

			throughout the UK. We would like to offer feedback from our perspective as a growing grassroots movement with extensive experiences of interactions - many via social media - with parents (particularly mothers), breastfeeding advocates and communities involved in breastfeeding support. Neither IFSUK nor I Support You, the arm of IFSUK dedicated to communicating scientific findings to parents, has any links to or income from any companies or organisations that profit from breast milk substitutes, infant food or infant feeding products including and not limited to bottles, teats, dummies, shields and breast pumps. We also do not have any contact with such companies. In general we commend the guidelines and note that they are exceptionally clearly set out. In particular the inclusion of material specifically aimed to mothers/mothers-to-be is helpful and it is extremely encouraging to see that this material also contains an infographic summarising the absolute risks of HIV-transmission to babies in specific feeding scenarios (p106 of the guideline). We would further like to commend you for your efforts to destigmatise formula feeding for mothers living with HIV and we are confident that many will find this advice extremely helpful. We are concerned, however, that the following section in the current draft guidelines may potentially lead to unintentional misrepresentation: (p82) "Ideally, women should be advised to breastfeed for as short a time as possible, to exclusively breastfeed for the first 6 months, and to cease breastfeeding if they have breast infection/mastitis or if they or their infant has gastro-intestinal symptoms. They should be given clear information, including how to manage common complications of breastfeeding, and have ready access to clinical advice and peer support. They should be reviewed monthly with their baby for HIV RNA viral load testing until they stop breastfeeding." We assume that this section refers to the scenario whereby a mother fulfills the criteria specified in recommendation 9.4.3. but chooses, through discussion with her HIV MDT, to breastfeed, against the general recommendation of 9.4.1. (to avoid HIV exposure to the baby through exclusive formula feeding). It is possible that the statement in 9.4.3. could be misinterpreted or misquoted out of context and consequently convey that the general recommendation of BHIVA is that "women [living with HIV] should be advised to… exclusively breastfeed for the first 6 months". This would be counter to what we understand of the general recommendation of BHIVA as stated in 9.4.1. We would advise that the statement above might be reframed in some way to make it clearer that this is a specific recommendation with respect to ensuring the safety of breastfeeding when the mother is HIV positive, once that has been mutually decided on the right way forward with the HIV MDT. Our concern with this section of the guidelines arises from our knowledge of the online lay literature on infant feeding in which we have previously noted examples of statements that may have, perhaps unintentionally, taken previous guideline text out of context and given rise to claims in social media discussions, blogs etc. that the risks of HIV transmission through breastfeeding in the UK context	This has been clarified

			might be "virtually zero". In addition, in this type of literature it is not always made entirely clear that feeding decisions for mothers living with HIV should involve careful counseling and guidance with their specialist HIV MDT. These points may reflect divergence, possibly unintentional, between the lay literature and what the present guideline authors say aligns with the current balance of scientific evidence. We have also noted that the guideline does not include any specific recommendations with regard to how feeding should be managed if a mother has planned to breastfeed but then at some later stage, supplementation with formula becomes needed, perhaps for some medical reason. Many mothers aiming to exclusively breastfeed, particularly in high-income settings such as the UK, experience problems such as delayed onset of lactation (1), which can result in the infant experiencing jaundice, excessive weight loss or hypernatremia if supplementation is not provided promptly (this may only be temporarily needed). These problems are more common in first-time mothers but many risk factors are reported and the proportion of babies affected by delays in milk production can be high even in cohorts where mothers are strongly motivated to breastfeed and have received good lactation support (2). We therefore feel that it may be necessary to consider this aspect in guiding mothers so that it is clear what an HIV-positive mother should do if she has decided on exclusive breastfeeding with her HIV MDT but subsequently some indication arises to supplement with formula, even for a short time only. We understand that there is evidence to indicate that mixed feeding (both breastfeeding and giving formula at the same time) is associated with a much greater risk of HIV transmission, even where the mother is virologically suppressed. In summary, we commend the authors for the production of this very useful guideline and note some minor areas for possible consideration and clarification. Thank you for considering our comments and we appreciate the clarity and attention given to ensuring that all mothers can safely feed their babies. Erin Williams PhD (co-founder), Stephanie Maia MSc (co-founder) and Emma Veitch PhD (contributor) Infant Feeding Support UK. www.infantfeedingsupport.org	This has been addressed
37.	Rosalie Hayes	NAT (National AIDS Trust	NAT response to BHIVA guidelines for the management of HIV infection in pregnant women 2018 NAT (National AIDS Trust) is the UK's HIV policy and campaigning charity. NAT welcomes the expansion of the guidelines on the topics of infant feeding and post-natal management of mothers living with HIV. In particular, NAT supports the inclusion of recommendation 9.4.2 for clinicians to recognise the financial and psychological impact of advising mothers living with HIV not to breastfeed, requiring support for mothers from their HIV MDT, and the inclusion of a recommendation for the provision of free formula to mothers living with HIV. This was also recommended by NAT in our policy	All actioned and added – infant feeding all moved to section 9 so not split across two sections

			briefing 'Access to formula milk for mothers living with HIV in the UK'. Section 10 – Post-natal Management NAT supports the inclusion of recommendation 10.4.1 that women who are advised not to breastfeed should be provided with free formula milk to prevent vertical transmission. However, we would suggest that this recommendation should either a) be moved into the following section (section 10.4 support services) or b) have its own section. Currently, the recommendation is within the section on suppression of lactation and appears unrelated to the preceding text. The recommendation would be strengthened with the inclusion of supporting evidence. We suggest including evidence along the following lines: When mothers living with HIV are advised not to breastfeed, this can have a significant financial impact. There is a risk that some mothers with insufficient finances will forgo their own nutritional needs in order to afford formula for their infant – compromising their own health and potentially compromising the effectiveness of their HIV treatment.[1] Mothers with irregular immigration status and no recourse to public funds (NRPF) and mothers with low income are particularly vulnerable to these barriers.[2] The provision of free formula milk, and the appropriate equipment to use it, alleviates any financial burden attached to this key prevention tool.[3] This ensures that mothers can make decisions on how to feed their infant without being influenced by cost. Free provision of formula milk also has the potential to retain women in HIV care post-pregnancy.[4] There are different ways that formula milk may be provided. We also recommend including an example of free formula milk provision to act as further guidance for clinicians and commissioners and to support them to identify possible approaches they could take. The following example is extracted from our policy briefing: Formula Milk Scheme at Jonathan Mann Clinic, Homerton Hospital [5] 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. NAT	Agreed – now moved to section 9.4 where it fits better

			February 2018 [1] Karpf B, Smith G, Spinks R. Affording formula: HIV-positive women's experiences of the financial strain of infant formula feeding in the UK. Abstract O27. HIV Med 2017; 18 Suppl S1: 3–13. [2] NAT. 2017. Policy briefing: access to formula milk for mothers living with HIV in the UK. Available at: https://www.nat.org.uk/publication/policy-briefing-access-formula-milk-mothers-living-hiv-uk [3] Ibid. [4] 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 [5] Other examples of formula milk schemes can be found in NAT. 2017. Policy briefing: access to formula milk for mothers living with HIV in the UK.	
38.	Ceri Evans	Queen Mary University of London	Thank you for the opportunity to take part in this consultation process. I think the guideline is excellent and comprehensive. In particular, I agree with the updated recommendations for "very low risk" situations, and with the guidance for the management of infants born to mothers wishing to breastfeed, which I believe to be pragmatic, more culturally sensitive, and ultimately safer for the child. I have a one extremely minor comment that may help make the guidance clearer. On page 96 (Appendix 4: Drug Dosing for Infants), the duration of oral dosing of AZT for monotherapy is stated as 2 weeks. However, as per the recommendations this would only be the case for "very low risk" infants, and to avoid confusion it may be clearer to state a 2-week duration for "very low risk" situations, and a 4-week duration for "low risk" situations.	This has been addressed
39.	Susan Cole	Sophia Forum	(BHIVA guidelines for the management of HIV infection in pregnant women 2018 – Sophia Forum comment	

			• 1.3 Patient Involvement - Sophia Forum pleased BHIVA recognises the importance of patient and community representatives in guideline development and that a patient was involved in all aspects of guideline development. Meaningful involvement of people living with HIV is crucial - too often there is merely tokenistic involvement. • We welcome the use of more acceptable language for PLWH, i.e. women living with HIV (rather than HIV infected women)/ Recommendations and auditable outcomes • We welcome the recommendations for psychosocial care of women living with HIV and sexual health screening. • We ask for clarification about therapeutic drug monitoring for pregnant women who were already on cART prior to pregnancy – is this something that can be offered routinely or is offered as soon as a woman stops being virally suppressed? One of our trustees living with HIV developed resistance to two classes of drugs during pregnancy when her viral load rose inexplicably at 33 weeks despite perfect adherence. • We recognise that in the UK and other resource rich setting that formula milk is the safest way to feed babies and in the guidelines you acknowledge there maybe financial repercussions for women who abstain from breast feeding, however particularly in the current climate of austerity and certainly in the case for women with HIV without recourse to public funds, the financial repercussions can be devastating. Some women are forced to go hungry, compromise their own health and may be forced to breastfed despite not wishing to. We ask that BHIVA calls on the Government to provide free formula milk for babies of mothers with HIV who cannot afford it. Psychosocial care of women living with HIV during and after pregnancy • We welcome that this section has been given greater prominence and has been expanded, as it is an area of particular relevance to women with HIV, who are disproportionately affected by mental health issues, which often intersects with other issues. We note you acknowledge women living with HIV may be at risk of intimate partner violence and endorse the NICE antenatal guidelines that all pregnant women be asked about domestic violence – however women with HIV are MORE at risk of IPV, evidence by both international and UK research, we ask that this is emphasised in the guidelines, particularly as it can impact on HIV care, including attending for care and taking ARVs. • We welcome the recognition that social and/or immigration issues affect many women living with HIV. We are concerned that some women living with HIV may be afraid of seeking medical care, even in pregnancy, fearful their data may be handed over to immigration officials. • We welcome the recognition of the value of trained peer-support workers, who we feel should be a crucial part of the multidisciplinary team.	Sentence added in PK section We advocate this in the guidelines

			Neonatal management • We welcome the recognition that abstaining from breastfeeding can have financial and psychological repercussions for women and the advice given in section 10.4. We call for free formula milk for women living with HIV for their babies, particularly for those who find paying for it difficult. • We recognise that in the UK the safest method is formula feeding, however welcome that women who are virally suppressed and choose to breastfed are now supported to do so, but informed of the low risk of transmission. Postpartum and postnatal management of women: • We welcome the recognition of peer mentoring as being important to improve adherence. • We welcome the recognition of the importance of postnatal follow up by a member of the multi-disciplinary team, a time when a woman living with HIV may be feeling particularly vulnerable. • We welcome that women not breastfeeding will be offered cabergoline to suppress lactation. • We welcome that women with support needs will be referred to appropriate services, particularly those in the community. Additional comment: • Sophia Forum calls for IVF support on the NHS for women with HIV who need it.	Additional comment: this is beyond the scope of the guidelines
40.	Heather Kale	Lactation Consultants of Great Britain	LCGB Response to BHIVA consultation on the management of pregnancy for women living with HIV in the UK LCGB welcomes the opportunity to comment on the guidelines on 'The management of pregnancy for women living with HIV', particularly in light of the enhanced detail around the controversial area of breastfeeding. Rather than duplicate the information provided to BHIVA by Pamela Morrison, (IBCLC and LCGB member), LCGB would like to fully endorse Pamela's contribution to the guidelines with the following additional information about IBCLC lactation consultants practising in the UK: Lactation Consultants of Great Britain (LCGB) is the professional association for International Board Certified Lactation Consultants (IBCLCs) in the UK, a professional voice for breastfeeding. LCGB's members can advise and consult on practice and protocols related to infant feeding in the UK. IBCLCs work in a variety of settings including the NHS, private practice and voluntary roles. As such, should an HIV+ mother in the antenatal period be considering breastfeeding, or is breastfeeding following the birth, to have contact with an IBCLC would enhance her opportunity and ability to successfully breastfeed her child. LCGB's Mission Statement: "Lactation Consultants of Great Britain, the professional voice for	Now specify encouraging women to share HIV diagnosis with lactation consultants if involved

			breastfeeding, is working to create a society where every mother is comfortable breastfeeding her baby with access to professional help if she needs it." ..this includes mothers with HIV. As IBCLCs we are ideally placed to provide this support to facilitate informed decision making alongside the mother-baby dyad and their health care team, and to facilitate breastfeeding when a mother chooses to. IBCLCs are often infant feeding leads in both community and hospital settings and many run specialist breastfeeding / infant feeding services throughout the UK. Families / women who wish to consider breastfeeding should be referred to such services. Page 30 of the WBTI (World Breastfeeding Trends Initiative) report, maps out pre-registration education on breastfeeding and HIV. WBTi report 2016. The WBTi report also highlights gaps and recommendations for the UK, HIV and breastfeeding (Indicator 8, page 50.) The full WBTi report can be accessed through the link below: https://ukbreastfeedingtrends.files.wordpress.com/2017/03/wbti-uk-report-2016-part-1-14-2-17.pdf In August 2017 The World Health Organisation published new guidance which helps to protect breastfeeding as a human right. The statement reads: "Breastfeeding is a human rights issue for both the child and the mother" (United Nations Office of the High Commissioner for Human Rights, 2016). It declares that children have the right to life, survival, and development and to the highest attainable standard of health, as well as to safe and nutritious foods. Breastfeeding must be considered an integral component of these rights. Breastfeeding is also a rights issue for women (Galtry, 2015). A mother is not obligated to breastfeed her child, but no one may interfere with a mother's right to breastfeed her child (Kent, 2006). Women have the right to accurate, unbiased information needed to make an informed decision about breastfeeding and the right to an environment that enables them to carry it out. The importance of breastfeeding is now widely understood. It reduces child mortality, increases child cognition, improves maternal and child health, and fosters economic development (Victora et al., 2016). 1 In the context of a mother who is HIV+ the implications of this statement are inevitably more complex than for other mothers, however her health status should not preclude a mother from the protection that it affords her in terms of her feeding choices. In light of the new evidence concerning transmission of the HIV virus through breastmilk and how this can best be prevented, the sentence, "Women have the right to accurate, unbiased information needed to make an informed decision about breastfeeding and the right to an environment that enables them to carry it out." becomes even more pertinent. The BHIVA guidelines state;	

			9.4.4 They should be given clear information, including how to manage common complications of breastfeeding, and have ready access to clinical advice and peer support. It would be of use here to specify how to access specialist breastfeeding support. The document published by LCGB 'Who's Who in Breastfeeding Support' provides this information. See doc: http://www.lcgb.org/wp-content/uploads/2018/02/Whos-Who-2017-Oct-17-1.pdf Should you need any further information from LCGB or have any questions about the role of the IBCLC in the UK and how they can support HIV+ mothers please do not hesitate to contact us. 1. Grummer-Strawn LM, Zehner E, Stahlhofer M, et al. New world health organization guidance helps protect breastfeeding as a human right. Matern Child Nutr. 2017;13:e12491. https://doi.org/10.1111/mcn.12491	