Received: 8 June 2023 | Accepted: 5 November 2023

DOI: 10.1111/hiv.13583

SHORT COMMUNICATION

Guidelines and practice of breastfeeding in women living with HIV—Results from the European INSURE survey

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Abstract

Introduction: Antiretroviral therapy (ART) is integral to HIV prevention, including averting vertical transmission. The World Health Organization (WHO) recommends ART and breastfeeding for all women living with HIV for at least 12 months post-partum [1, 2]. Much of the data on HIV transmission through breastfeeding comes from low-resource settings, with a paucity of data on breastfeeding-related HIV transmission in women living with HIV in other settings. Women Against Viruses in Europe (WAVE), part of the European AIDS Clinical Society (EACS), aims to improve the standard of care for women living with HIV and sought to gain an understanding of breastfeeding guidelines and practice in women living with HIV across Europe.

Methods: A steering group convened by WAVE developed a survey to collate information on breastfeeding trends, practice, and guideline recommendations for women living with HIV in Europe and to establish interest in becoming involved in a collaborative breastfeeding network. The survey was disseminated to 31 countries in March 2022.

Results: In total, 25 eligible responses were received: 23/25 (92%) countries have HIV and pregnancy guidelines; 23/23 (100%) guidelines refer specifically to breastfeeding; 12/23 (52%) recommend against breastfeeding; 11/23 (48%) offer an option if certain criteria are met; 12/25 (48%) reported that the number of women living with HIV who breastfeed is increasing; 24/25 (96%) respondents were interested in joining a network on breastfeeding in women living with HIV.

Conclusions: Recommendations vary, and nearly half of the guidelines recommend against breastfeeding. Many countries report an increase in breastfeeding. WAVE will establish a collaborative network to bridge data gaps, conduct research, and improve support for women living with HIV who choose to breastfeed.

KEYWORDS

breastfeeding, HIV, infant feeding, pregnancy, women living with HIV

INTRODUCTION

The high effectiveness of antiretroviral therapy (ART) has transformed the lives of people living with HIV. In addition, ART is the most important measure of HIV prevention, including prevention of vertical HIV transmission. However, there is still controversy regarding the small risk of HIV transmission in the setting of effective maternal ART, where there is access to safe, affordable alternatives to breast milk [1].

The World Health Organization (WHO) reports the rate of vertical transmission without ART, or other specific interventions, as ranging from 15% to 25% in Europe and the USA, and from 25% to 45% in low-resource settings, where breastfeeding is the norm [2,3]. In low-resource settings, the estimated risk of HIV transmission attributable to breastfeeding, in the absence of maternal or infant ART, is 25%–48% [4].

Rates of vertical transmission in high-resource settings, where mothers living with HIV are advised not to breastfeed, are reported as less than 0.5% [5,6]. There is increasing data, primarily from low-resource settings, on breastfeeding-associated transmission in the setting of maternal ART [7]. A large randomized controlled trial comparing the efficacy of maternal ART and prolonged infant ART (PROMISE IMPACT), conducted in Sub-Saharan Africa and India, reported a breastfeeding-associated HIV transmission rate of 0.3% and 0.7% at 6 and 12 months of breastfeeding, respectively, in 1 219 mother–infant pairs where mothers were taking combination ART. There was no increased risk of toxicity reported in these infants [8]. Of note, in the maternal ART group, only 41% of women had a viral load below the limit of detection at delivery or at their study entry visit 1 week postpartum.

The WHO recommends that women living with HIV breastfeed for at least 12 months but may continue breastfeeding up to 24 months or longer (similar to the general population) while being supported with adherence to ART [9]. The WHO recommends exclusive breastfeeding but states that mixed feeding is not an indication to stop breastfeeding in the presence of ART. These guidelines are recommended as global guidance regardless of HIV prevalence [1].

We know that, in high-resource settings, most guidelines recommend against breastfeeding for women living with HIV, and there is a paucity of data on breastfeeding-associated transmission in areas where there is continuous access to maternal ART and maternal and infant monitoring. In addition, there are reports of increased intention to breastfeed or actual breastfeeding in women living with HIV [5,10] and documented wish to breastfeed and fear of stigma in women living with HIV who do not breastfeed [11]. Research and collaboration is needed to inform guidance and best practice in these settings to provide best medical care during this period.

Women Against Viruses in Europe (WAVE), part of the European AIDS Clinical Society (EACS), is an initiative established in 2014 to promote the welfare of women living with HIV in Europe. WAVE sought to gather information on breastfeeding recommendations and practices for women living with HIV across Europe and to develop a collaborative network to share experience, bridge data gaps, and provide research opportunities to improve our understanding and to inform guidelines for healthcare providers.

This survey, conducted by the WAVE breastfeeding group, aims to review similarities and differences in breastfeeding recommendations for women living with HIV in Europe and create a conversation and supportive network for providers caring for women living with HIV who wish to breastfeed.

METHODS

A steering group consisting of healthcare providers, non-governmental organization representatives and researchers was established to develop a survey (Appendix A1) to review national guideline recommendations and country practices in relation to breastfeeding for women living with HIV. In addition, each country was asked about the trends in breastfeeding, current breastfeeding-related research, and willingness to participate in a network for collaboration and research. The survey, INSURE (HIV aNd BreaStfeeding in EURopE), consisted of 38 questions, including multiple choice and free text for descriptive answers. Not all of the questions were mandatory. The survey was developed and distributed via Jotform, which was also used to collate results. The steering group identified a contact person in each country across Europe to whom the survey link was sent. These contacts were mostly identified through EACS and WAVE networks. Thus, 31 contacts were emailed a link to the survey on 30 March 2022, requesting one response per country. Contacts were asked to link in with colleagues as needed to provide the most appropriate response for their country. The survey was closed on 9 May 2022, after a series of reminders were sent alerting respondents of the closing date.

RESULTS

In total, 25 responses were included in the final analysis. Some respondents omitted some questions, leading to different denominators throughout the results. The survey took a minimum of 12 min and a maximum of 43 min to complete, as recorded by Jotform. Respondents were encouraged to attach links to or files of referenced guidelines.

A flowchart of country responses in relation to HIV and pregnancy guidelines is shown in Figure 1. Responses were received from the countries listed in Table 1, which also presents country-specific survey responses. Where countries did not have national guidelines, responses were provided around country practices, which are included in the results. This is clearly indicated in Table 1.

Of the 23 countries with national guidelines, 12/23 (52%) reported that their guidelines recommend against breastfeeding, 11/23 (48%) offer an option to breastfeed if certain clinical criteria are met, and no countries offer an option to all women to breastfeed.

Although not specifically asked in the survey, three countries independently advised that, although their guidelines recommended against breastfeeding, if a woman wishes to breastfeed, she would be supported to do so where medically appropriate.

In total, 12/25 (48%) respondents reported that the number of women living with HIV who breastfeed in their country is increasing, 12/25 (48%) felt it was stable, and 1/25 (4%) felt it was decreasing.

Maternal viral load, duration/type of breastfeeding, and neonatal post-exposure prophylaxis

The survey asked a range of questions around conditions for breastfeeding:

Seventeen respondents (17/17 [100%]) reported that a suppressed maternal HIV viral load (within 4 weeks of estimated delivery date) was required to support breastfeeding.

Ten respondents (10/11 [91%]) reported that a suppressed viral load needs to be maintained for a minimum period of time during pregnancy.

One respondent (1/11 [9%]) reported that a suppressed viral load prior to conception is required for breastfeeding.

Five respondents (5/12 [42%]) reported that their guidelines include a recommendation on duration of breastfeeding.

Eleven respondents (11/20 [55%]) have a recommendation on the minimum age of introduction of solids.

Sixteen respondents (16/19 [84%]) reported that all infants born to women living with HIV (including breastfed and non-breastfed infants) receive post-exposure prophylaxis (PEP).

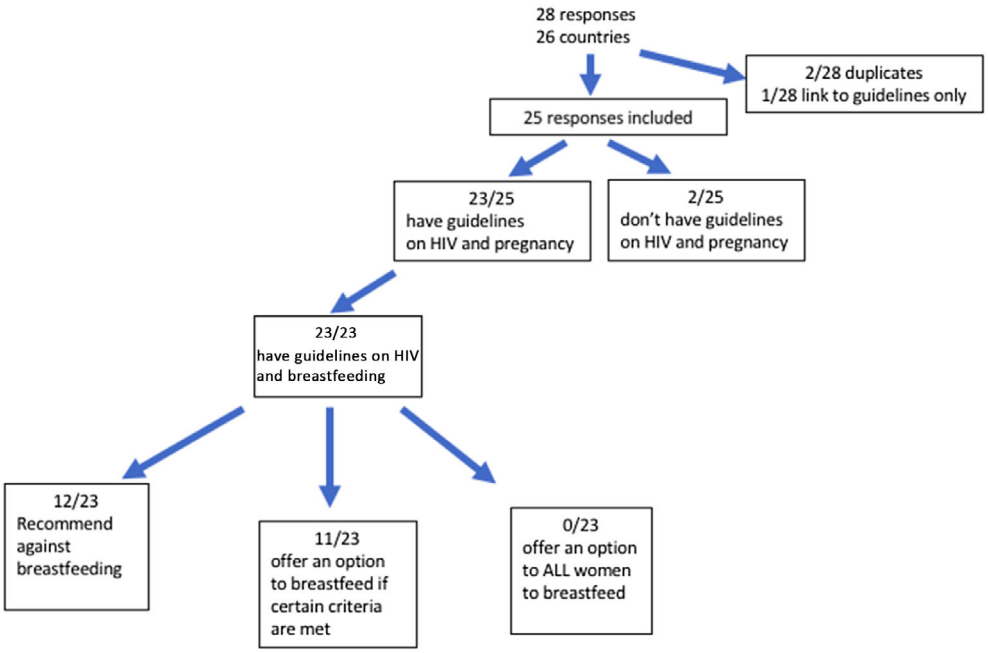

FIGURE 1 Country responses: HIV and pregnancy guidelines.

TABLE 1 Survey responses on breastfeeding by country.

Country	Do you have guidelines for management of HIV in pregnancy in your country?	Do your guidelines refer to breastfeeding?	Breastfeeding options: Recommend against, offer if certain criteria are met, offer to all	Is there a recommended frequency for maternal viral load testing during breastfeeding?	Is there a recommended frequency for infant viral load testing during breastfeeding?	Is there a recommendation for infant viral load testing after complete cessation of breastfeeding?	Do you have patient information resources (for example leaflets) on breastfeeding for women living with HIV?
Austria	Yes	Yes	In certain cases	Yes	Yes	Yes	No
Belgium	No[a]		N/A	No[a]	No[a]	No[a]	No[a]
Denmark	Yes	Yes	In certain cases	Yes	Yes	Yes	Yes
Finland	Yes[b,c]	Yes	Recommend against	Yes	Yes	Yes	No
France	Yes	Yes	Recommend against				
Germany	Yes	Yes	In certain cases	Yes	Yes	Yes	No
Greece	Yes[d]	Yes	In certain cases	Yes	Yes	Yes	No
Ireland	Yes[e]	Yes	Recommend against	No	No	No	Yes
Israel	No		N/A	No	No	No	No
Italy	Yes	Yes	Recommend against				
Kyrgyztan	Yes	Yes	In certain cases	No	Yes	No	Yes
Latvia	Yes	Yes	Recommend against	No	No	No	No
Norway	Yes[c]	Yes	Recommend against	Yes	Yes	Yes	Yes
Poland	Yes	Yes	In certain cases	No	No	No	No
Portugal	Yes	Yes	In certain cases	Yes	Yes	Yes	No
Czech Republic	Yes	Yes	Recommend against	No	No	No	No
Romania	Yes	Yes	Recommend against	No	No	No	No
Russia	Yes	Yes	Recommend against				
Spain	Yes	Yes	Recommend against	No	No	No	Yes
Sweden	Yes	Yes	Recommend against	No	No	No	No
Switzerland	Yes	Yes	In certain cases	Yes	Yes	Yes	No
The Netherlands	Yes[f]	Yes	In certain cases	Yes	Yes	Yes	Yes

TABLE 1 (Continued)

Country	Do you have guidelines for management of HIV in pregnancy in your country?	Do your guidelines refer to breastfeeding?	Breastfeeding options: Recommend against, offer if certain criteria are met, offer to all	Is there a recommended frequency for maternal viral load testing during breastfeeding?	Is there a recommended frequency for infant viral load testing during breastfeeding?	Is there a recommendation for infant viral load testing after complete cessation of breastfeeding?	Do you have patient information resources (for example leaflets) on breastfeeding for women living with HIV?
Turkey	Yes	Yes	Recommend against	Yes	Yes	Yes	Yes
Ukraine	Yes	Yes	In certain cases	Yes	Yes	Yes	Yes
United Kingdom	Yes	Yes	In certain cases	Yes	Yes	Yes	Yes

[a]A working group to develop guidelines on HIV and pregnancy was established in Belgium in November 2021; these guidelines will refer to breastfeeding.
[b]Finland's guidelines are unofficial but available and followed throughout all of Finland.
[c]Norway and Finland indicated that, although their guidelines recommend against breastfeeding, women who have a suppressed viral load and wish to breastfeed are supported to do so.
[d]General advice against breastfeeding, but if the mother wishes to breastfeed, she is closely monitored and breastfeeding is stopped if viral load >50 copies/mL.
[e]Guidelines in Ireland are currently being updated to include criteria for monitoring if a woman does choose to breastfeed.
[f]Dutch guidelines recommend formula feeding as the safest option; women who wish to breastfeed are supported if certain criteria are met.

Twelve respondents (12/16 [75%]) reported that PEP is not extended in infants who are breastfed.

Three respondents (3/16 [19%]) reported that PEP is extended in some breastfed infants.

One respondent (1/16 [6%]) reported that PEP is extended in all breastfed infants.

Information on breastfeeding

Six respondents (6/20 [30%]) have dedicated healthcare workers to educate women living with HIV on breastfeeding.

Thirteen respondents (13/20 [65%]) have a multidisciplinary approach for management of women living with HIV who wish to breastfeed.

Countries reported a variety of different healthcare workers in their multidisciplinary team, including midwives, paediatricians, gynaecologists, infectious disease specialists, clinical nurse specialists, social workers, and case manager/peer workers from an non-governmental organization.

Laws surrounding HIV and breastfeeding

Twenty-two respondents (22/25 [88%]) reported that there were no known cases of women living with HIV breastfeeding who had been reported to the police or social services or been prosecuted or convicted due to breastfeeding. Three respondents (3/25 [12%]) reported that this has occurred in their country, and two respondents stated that social services had been informed.

Ten respondents (10/25 [40%]) said breastfeeding is exempt from laws concerning HIV exposure and/or transmission, and 15 respondents (15/25 [60%]) reported that breastfeeding is not exempt from laws concerning HIV exposure and/or transmission.

Research on HIV and breastfeeding

Eight countries (8/25 [32%]) have research studies on breastfeeding in women living with HIV, and some reported multiple studies. At a national level, five research studies (5/9 [56%]) are ongoing, two (2/9 [22%]) have been published [10–13], and two research studies (2/9 [22%]) have been completed. At the local level, three research studies (3/4 [75%]) are ongoing, and one respondent reported that their research studies (1/4 [25%]) have been published [14,15].

One respondent (1/6 [17%]) reported having a breastmilk biobank.

Twenty-four (24/25 [96%]) respondents would like to collaborate in data collection around breastfeeding in women living with HIV coordinated by WAVE.

DISCUSSION

Through this survey, we sought to better understand the current situation and transition of guidelines and practice in Europe in regard to breastfeeding in women living with HIV. Our results demonstrate that countries report an increasing number of women who decide to breastfeed and heterogeneity in guidelines and practice across respondents.

There is adequate data in HIV serodifferent sexual couples to support the statement 'undetectable = untransmissible' (U = U) regarding the ability of effective ART to prevent sexual transmission of HIV [16,17]. We do not have the same level of evidence to apply U = U to the breastfeeding situation. The risk is lower when the mother's viral load is not detectable, but breastfeeding-associated transmissions in the setting of effective maternal ART have been reported [13,18,19].

Despite many guidelines recommending against breastfeeding, some women will choose to breastfeed. Comments in the survey revealed that clinical practice differs from what is recommended in guidelines. To minimize risk in a supported way, many countries offer support to women who choose to breastfeed despite their national guidelines recommending against breastfeeding. Freeman-Romilly et al. describe providing a 'managed risk' plan for women living with HIV who want to breastfeed their infants, including 'Ten safer breastfeeding rules' and 'The Safer Triangle' [13].

We need to recognize the complexities of breastfeeding in women living with HIV who wish to breastfeed. It must be noted that formula feeding is the only method of feeding that has zero risk of HIV transmission to the infant, and this needs to be discussed with the mother. However, taking a hard-line approach to counselling against breastfeeding may result in a mother breastfeeding in secret and a lost opportunity for education, adherence support, and close monitoring. Open conversation leading to shared decision making is important in understanding a mother's and parents' values, discussing risks and benefits, and providing education to ensure the best outcome for the infant [20]. We believe it is our duty to encourage and support an open discussion around breastfeeding in women living with HIV.

NOURISH-UK, an ongoing study exploring how new mothers/birthing parents living with HIV make decisions around feeding their babies in the UK, will help better inform guidelines and supports for parents by sharing experiences and offering peer support [21].

One-third of countries are already conducting research on breastfeeding in women living with HIV in their country. The vast majority of respondents would like to join a European network to bring together expertise in this area. Since the total number of breastfeeding women living with HIV is increasing but still small in most European countries, collaboration to increase our understanding is essential.

This survey is the first to review practices and guidelines in relation to breastfeeding in women living with HIV in Europe. Although guidelines themselves were not independently reviewed, the survey was sent to an informed group of clinicians, non-governmental organization representatives, and researchers, and—where national guidelines were available—verbatim fragments of the guidelines were gathered. This article has led to the development of a working group to review and translate guidelines across Europe. We received a broad range of responses but did not reach every country in Europe.

The establishment of the INSURE WAVE breastfeeding network will help fill the data gap and start a discussion in Europe around breastfeeding in women living with HIV.

CONCLUSIONS

Breastfeeding recommendations for women living with HIV vary across Europe. Many national guidelines recommend against breastfeeding, but some include management recommendations if women choose to breastfeed. Around half of the countries report an increase in the number of women living with HIV who are breastfeeding. Almost all of the respondents express a keen interest in joining a network supported by EACS/WAVE to expand our knowledge and research opportunities. This survey and the differences and similarities across countries will help bring respondents together to create a European platform for discussion and collaboration so that more data can be collected and a consensus reached on how best to support women living with HIV who want to breastfeed to do so safely.

AUTHOR CONTRIBUTIONS

A. Haberl, F. Lyons, A. Martinez Hoffart, H.l Albayrak, K. Aebi-Popp, H. Lyall, C. Feiterna-Sperling, C. Thorne and H. Scherpbier have made a substantial contribution to the concept and design of the survey. A. Keane, A. Haberl and F. Lyons were responsible for the analysis of data for the article. A. Keane, A. Haberl, F. Lyons drafted the article. A. Haberl, F. Lyons, A. Martinez Hoffart, H.

Albayrak, K. Aebi-Popp, H. Lyall, C. Feiterna-Sperling, C. Thorne, H. Scherpbier and A. Keane revised the article critically and approved the version to be published.

ACKNOWLEDGEMENTS

The authors thank all the authors and respondents for their contribution to the paper.

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REFERENCES

1. WHO. Consolidated Guideline on Sexual and Reproductive Health and Rights of Women Living with HIV. WHO; 2017.
2. Rates of mother-to-child transmission of HIV-1 in Africa, America, and Europe: results from 13 perinatal studies. The working group on mother-to-child transmission of HIV. *J Acquir Immune Defic Syndr Hum Retrovirol*. 1995;8(5): 506-510.
3. WHO. HIV Transmission Through Breastfeeding; A review of available evidence. 2007 Update. Geneva. 2008.
4. De Cock KM, Fowler MG, Mercier E, et al. Prevention of mother-to-child HIV transmission in resource-poor countries: translating research into policy and practice. *JAMA*. 2000; 283(9):1175-1182.
5. The Integrated Screening Outcomes Surveillance Service. ISOSS HIV Report 2022. GOV.UK2022. Available from: NHS Infectious Diseases in Pregnancy Screening Programme, Integrated Screening Outcomes Surveillance Service HIV report 2022.
6. Jiménez de Ory S, González-Tomé MI, Fortuny C, et al. New diagnoses of human immunodeficiency virus infection in the Spanish pediatric HIV cohort (CoRISpe) from 2004 to 2013. *Medicine (Baltimore)*. 2017;96(39):e7858.
7. Bispo S, Chikhungu L, Rollins N, Siegfried N, Newell ML. Postnatal HIV transmission in breastfed infants of HIV-infected women on ART: a systematic review and meta-analysis. *J Int AIDS Soc*. 2017;20(1):21251.
8. Flynn PM, Taha TE, Cababasay M, et al. Prevention of HIV-1 transmission through breastfeeding: efficacy and safety of maternal antiretroviral therapy versus infant nevirapine prophylaxis for duration of breastfeeding in HIV-1-infected women with high CD4 cell count (IMPAACT PROMISE): a randomized, open-label, clinical trial. *J Acquir Immune Defic Syndr*. 2018;77(4):383-392.
9. Guideline: Updates on HIV and Infant Feeding: The Duration of Breastfeeding, and Support from Health Services to Improve Feeding Practices Among Mothers Living with HIV. 2016.
10. Haberl L, Audebert F, Feiterna-Sperling C, et al. Not recommended, but done: breastfeeding with HIV in Germany. *AIDS Patient Care STDS*. 2021;35(2):33-38.
11. Nyatsanza F, Gubbin J, Gubbin T, et al. Over a third of childbearing women with HIV would like to breastfeed: a UK survey of women living with HIV. *Int J STD AIDS*. 2021;32(9): 856-860.
12. Kasadha B, Tariq S, Nyatsanza F, Freeman-Romilly N, Namiba A, Rai T. Stakeholder engagement is essential to maximise the impact of research on infant feeding in the context of HIV. *Ther Adv Infect Dis*. 2021;8. doi:10.1177/20499361211057970
13. Freeman-Romilly N, Nyatsanza F, Namiba A, Lyall H. Moving closer to what women want? A review of breastfeeding and women living with HIV in the UK and high-income countries. *HIV Med*. 2020;21(1):1-8.
14. Khamidulina RM, Katyagina MG, Zolotova IS, Zuganshina LE. Assessing the effectiveness of prevention of mother-to-child HIV transmission. *Kazan Med J*. 2021;102:176-184.
15. Kozyrina NV, Ladnaya NN, Sokolova EV, et al. Mother-to-child HIV transmission during breastfeeding. *Epidemiol Infect Dis*. 2015; 10-14.
16. Rodger AJ, Cambiano V, Bruun T, Vernazza P, Collins S, Degen O. Risk of HIV transmission through condomless sex in serodifferent gay couples with the HIV-positive PARTNER taking suppressive antiretroviral therapy (PARTNER): final results of a multicentre, prospective, observational study. *Lancet*. 2019; 393(10189):2428-2438.
17. Cohen MS, Gamble T, McCauley M. Prevention of HIV transmission and the HPTN 052 study. *Annu Rev Med*. 2020;71:347-360.
18. Malaba TR, Nakatudde I, Kintu K, Colbers A, Chen T, Reynolds H. 72 weeks post-partum follow-up of dolutegravir versus efavirenz initiated in late pregnancy (DolPHIN-2): an open-label, randomised controlled study. *Lancet HIV*. 2022; 9(8):e534-e543.
19. Flynn PM, Taha TE, Cababasay M, Butler K, Fowler MG, Mofenson LM. Association of maternal viral load and CD4 count with perinatal HIV-1 transmission risk during breastfeeding in the PROMISE postpartum component. *J Acquir Immune Defic Syndr*. 2021;88(2):206-213.
20. Johnson G, Levison J, Malek J. Should providers discuss breastfeeding with women living with HIV in high-income countries? an ethical analysis. *Clin Infect Dis*. 2016;63(10):1368-1372.
21. Nuffiled Department of Primary Care Health Science. NOURISH-UK. Available from: https://www.phc.ox.ac.uk/research/health-experiences/Nourish_UK

How to cite this article: Keane A, Lyons F, Aebi-Popp K, et al. Guidelines and practice of breastfeeding in women living with HIV—Results from the European INSURE survey. *HIV Med*. 2023;1-7. doi:10.1111/hiv.13583

APPENDIX A1: HIV and Breastfeeding in Europe (INSURE) Guidelines, studies, statistics and practice of breastfeeding in women living with HIV.

https://www.eacsociety.org/media/hiv_and_breastfeeding_in_europe_insure_.pdf