

ORIGINAL ARTICLE

Medically assisted reproduction for people living with HIV in Europe: A cross-country exploratory policy comparison

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Abstract

Objective: To explore the availability and accessibility of medically assisted reproduction (MAR) for people living with HIV in Europe, including the feasibility of cross-border care.

Methods: We used a polymorphous engagement approach, primarily based on digital and email-based interviews with representatives of national HIV organizations, clinical researchers (infectious disease and/or infertility specialists), European and national professional societies (fertility and/or infectious disease), national regulatory authorities and individual clinics in 14 countries in the WHO European region. The research design and results were also informed by two surveys and a review of the secondary literature, news articles and clinic websites.

Results: Although MAR is possible for people living with HIV in 12 out of the 14 countries mapped, accessing services can be challenging for logistical or financial reasons. People living with HIV also face barriers to MAR independent of their HIV status, such as limitations on single women and same-sex couples accessing services. Cross-border care is available for most patients who are self-financing but is limited for publicly funded patients.

Conclusions: Even when MAR is available to and accessible for people living with HIV, there may still be barriers to treatment. Further research on patient experiences is needed to understand these discrepancies between availability and accessibility on paper and in practice.

KEYWORDS

Europe, fertility, HIV, law, medically assisted reproduction (MAR), policy

INTRODUCTION

As advances in treatment have transformed HIV into a chronic, manageable disease, increasing attention has been paid to fertility desires and options for incorporating family planning into HIV responses ([1-3], Friedman

et al. [4]). Historically, many researchers, clinicians and national guidelines have argued for the use of medically assisted reproduction (MAR) in order to reduce the risk of partner-to-partner transmission [5]. Technological approaches include sperm-washing with intrauterine insemination (IUI), *in vitro* fertilization (IVF) or intracytoplasmic

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sperm injection (ICSI). Increasingly, conception through condomless, heterosexual sex is endorsed in many countries (e.g. in the UK), as there is increasing recognition that HIV cannot be transmitted when people are on effective treatment [6,7].

However, MAR, such as IUI or IVF/ICSI, may be needed to treat infertility in people living with HIV. HIV status may decrease fertility and/or MAR outcomes, particularly in women, although more research is needed on this issue [8-13]. In cis-women (hereafter referred to as women/females), this may be related to higher incidence of pelvic inflammatory diseases and tubal diseases, and the potential effect of HIV status on the endocrine system. In cis-men (hereafter referred to as men/males), HIV may negatively affect sperm quality. MAR is also needed to treat single women or same-sex female couples.

Professional bodies such as the European Society of Human Reproduction and Embryology (ESHRE) and the American Society for Reproductive Medicine (ASRM) do not consider HIV status as a reason to deny MAR treatment (ESHRE Guideline Group on Viral infection/disease et al. [14]; ASRM [15]). Globally, however, there is limited access to fertility treatments for people living with HIV. This is partly due to disparities in access to fertility treatments in general, but also due to a variety of legislative, policy and social barriers specific to people living with HIV.

In this article, we explore the availability and accessibility of MAR for people living with HIV in the WHO European Region, focusing on 14 countries. Availability refers to: (1) whether or not MAR for PLWHIV is performed in the country and (2) whether or not there are enough clinics that provide such services. Accessibility refers to financial affordability, physical barriers to clinics – such as long travel times – access to information about treatment options and pathways, and administrative or social barriers ([16]; see also Präg and Mills [17]).

Overall, the policy frameworks regulating access and availability encompass a mosaic of laws at supranational (i.e. EU) and national levels, professional guidelines, guidelines from national regulatory authorities and individual clinic policies. These policy frameworks relate not only to reproductive health, but also to biosecurity, occupational safety and equality/discrimination. Although MAR is possible for people living with HIV in 12 out of the 14 countries mapped, accessing services can be challenging for logistical or financial reasons, particularly if few clinics provide services or if patients must pay for it themselves. In some cases, people living with HIV also face barriers to MAR regardless of their HIV status, such as restrictions on access for single women and same-sex couples.

Finally, we examine the issue of cross-border care: under what circumstances is it possible for people living with HIV to access fertility treatment outside their country of residence if it is not available at home? In countries with established private sectors, non-resident patients who pay out of their own pockets can readily access services. However, in countries where care is primarily limited to the public sector, the situation is mixed. Not all public clinics have the capacity to take on fee-paying patients and, accordingly, limit services to residents only.

METHODS

Cross-country policy comparisons are methodologically challenging. First, policy mapping does not allow for an in-depth examination of any one country context. In devolved or federal systems, individual jurisdictions may have different policies on access and availability of services. Second, policy comparison is contingent on gathering information from busy individuals – in our case, primarily health professionals and civil society groups – who must prioritize helping patients over answering researchers' questions.

Third, policy entitlements – particularly in fertility care – are complicated. For example, in several interviews we were initially told that people living with HIV could access treatment, but on further probing discovered that lesbian couples could not, or that only a few clinics in the country offered services to people living with HIV. Related to this, patients, their families and advocacy groups often have experiences that conflict with those of health professionals and regulatory bodies, and different clinics have different policies, regardless of national regulations. An illustrative example comes from a survey of 140 fertility clinics in the US. When contacted by a researcher posing as a patient, 41% of clinics offered services to a male living with HIV; this figure was 63% when the researcher posed as a physician [18].

To address these challenges, we drew inspiration from anthropology, specifically Hugh Gusterson's approach of 'polymorphous engagement' as elaborated by Ulf Hannerz [19,20]. This is a long-established approach in ethnographic research used for collecting and synthesizing a wide range of data, often across disparate settings. Polymorphous engagement is particularly suitable for interacting with policy and clinical experts to explore an issue area. It is also flexible in that it allows data collection methods to be adapted throughout the course of the research. Additionally, we drew previous fertility policy comparison studies, including that of Wessman and colleagues who focused on MAR for people living with HIV in Nordic countries [21-23].

In 2019 we sent a quantitative survey to 106 clinics in four countries. Owing to an extremely low response rate ($n = 8$) we were unable to draw definitive conclusions. However, this experience informed the design of our second survey and interview questions ([Appendix 1](#)). In 2021 we developed a qualitative survey which was distributed by the Women Against Viruses in Europe network (WAVE) at the European AIDS Clinical Society (EACS). We asked about barriers to accessing fertility treatment, how treatment is financed, and what laws and guidelines affect access. There was a final text box for further comments. We received 15 responses from nine countries. However, because many of the responses were incomplete or raised further questions, we then used purposeful sampling to identify and contact experts individually for interviews.

We contacted representatives of national HIV organizations, health professionals (embryologists, infectious disease and/or infertility specialists), European and national professional societies (fertility and/or infectious disease), national regulatory authorities and individual clinics. National organizations and individual experts were identified through the websites of European and international organizations, including AIDS Action Europe, International Planned Parenthood Federation,

the European Society of Human Reproduction, and Embryology (ESHRE). We used Google Scholar to identify clinical researchers, primarily infectious disease and fertility specialists, who had published on HIV and MAR from 2015 to the present. We interviewed 29 individuals in 14 countries, although the nature of this information ranged from a single-sentence email to an hour-long Zoom meeting split over two sessions. Including the surveys, interviews and other correspondence, in total we received information from 52 people in 19 countries (see [Table 1](#)).

There are limitations to our approach, which relate to the general challenges of cross-country policy comparisons. In some countries there are regional differences in availability and accessibility, but a detailed discussion of this is outside the scope of this article. Second, the complexity of the issue meant that, at times, we received conflicting information. Third, it was challenging to contact experts and, as noted, the information provided was often incomplete. Some experts were enthusiastic about the issue and sent comprehensive emails or took time to answer all of our questions on Zoom and walk us through various hypothetical scenarios faced by patients. Others sent very short replies and did not respond to follow-up emails. To address the subsequent validity

TABLE 1 Countries and experts

Country	Category (number) of experts	Other responses
Austria	Healthcare (1) Researcher (1)	We interviewed the experts listed to the left in Table 1 . Additionally, we received survey responses and related correspondence from Belgium (4), Czech Republic (1) Denmark (3), Finland (1), Poland (2), Romania (1), Russia (1) Spain (3), Sweden (1) Switzerland (3), Ukraine (2) and UK (3) of which two (Finland and Sweden) were available for a follow-up interview and are also counted to the left. In both surveys, responses were limited and incomplete and, for this reason, the results are not included in Table 2 . However, we draw upon the second survey (2021) in our findings on barriers to treatment and stigma. We also used the survey results to corroborate the interview findings. We spoke to more experts in the UK than in other countries in order to explore the situation in England, Wales, Scotland and Northern Ireland
Belgium	Healthcare (1)	
Denmark	Healthcare (2)	
Finland	Healthcare (1) Civil society (1)	
France	Healthcare (1)	
Germany	Healthcare (1) Researcher (1)	
Ireland	Healthcare (1) Civil society (1)	
Israel	Healthcare (2)	
Norway	Healthcare (2) Civil society (1)	
Poland	Healthcare (1)	
Portugal	Healthcare (1)	
Spain	Health professional (1)	
Sweden	Healthcare (2) Civil society (1)	
United Kingdom	Healthcare (3) Regulatory authority (1) Civil society (2)	

issues – and in line with the polymorphous engagement approach – we relied on a wide range of other material to verify information: peer-reviewed literature, reports by HIV organizations, news articles and clinic websites. Where possible, we spoke to more than one expert per country from different categories within the healthcare system and civil society in order to take account of different perspectives (see also Calhaz-Jorge et al. [21] on the challenges of validation).

RESULTS

Overview of availability and accessibility of fertility treatment for people living with HIV

Treatment was on offer in 12 of the 14 countries we mapped; however, patients face both logistical and

financial challenges (see Table 2). Logistically, in most of the countries, few clinics offer services to people living with HIV. For example, in Norway and Denmark, MAR is only available for people living with HIV in the public sector and at one and two fertility clinics, respectively. Similarly, IVF for people living with HIV is offered at one clinic in Israel (IUI is also offered at a second clinic). In Sweden, the only service permitted is sperm washing (for men living with HIV) and subsequent IUI or IVF with ‘washed’ sperm; this is provided at one fertility clinic. There are no clinics in Ireland that offer services to people living with HIV. Based on our findings, it is relatively easier to find clinics that offer services in Belgium, Germany, Portugal, Spain and the UK. However, this differs by city or region, and the full range of services is not always available to people living with HIV.

In all the countries mapped there are requirements for separate laboratory facilities for handling and storing gametes from people living with HIV [see also ESHRE guidance

TABLE 2 Overview of access

	Is medically assisted reproduction available for people living with HIV (PLWH)?	How is MAR for PLWH funded? (private/self-financed or public/statutory insurance)	Notes on access
Austria	Yes	Mainly public	Treatment only available in a few clinics; not available for single women
Belgium	Yes	Public	Few barriers to access
Denmark	Yes	Public	Treatment only available in the public sector, at two clinics
Finland	Yes	Both	Treatment available at three clinics (one private, one public)
Germany	Yes	Both	Access (including funding) limited for non-married couples, same-sex couples and single women
France	Yes	Public	Only available at a few clinics
Ireland	No	N/A	No clinics in Ireland treat PLWH
Israel	Yes	Mainly public	Treatment available at two clinics; one clinic does IUI and one clinic does IVF
Norway	Yes	Public	Treatment only available in the public sector, at one clinic
Poland	Yes	Private	Treatment unavailable for same-sex couples and single women
Portugal	Yes	Both	IUI readily available, IVF offered at fewer clinics
Spain	Yes	Both	Few barriers to access
Sweden	No*	Public	Only sperm-washing available, and only at one public clinic
United Kingdom	Yes	Both	In England, access to publicly funded MAR is highly dependent on region, independent of HIV status; especially for same-sex couples and single women; treatment for PLWH is available in England, Scotland and Wales; patients from Northern Ireland can travel to England for publicly funded treatment.

Abbreviations: IUI, intrauterine insemination; IVF, *in vitro* fertilization; MAR, medically assisted reproduction.

* sperm washing is an exception.

on laboratory safety (ESHRE Guideline Group on Viral infection/disease et al. [14]) and on good practice in IVF laboratories (ESHRE Guideline Group on Good Practice in IVF Labs et al. [8]). Specifically, in the EU context, the European Union Tissues and Cells Directive (2004), along with subsequent Commission Directives, requires separate laboratory facilities for handling and storing biological material from people living with a chronic infectious disease [24]. According to respondents, many clinics are unable or unwilling to provide these extra facilities due to cost or space constraints. However, in some countries, such as Belgium, if a clinic does not provide services to people living with HIV, they are required to refer patients to a clinic that does.

Individual barriers to treatment

Patients and potential patients face barriers that are shared by most people seeking fertility treatment, regardless of HIV status. Legal and financial entitlements to fertility treatment differ significantly across European countries and individuals may be unable to access treatment due to cost, or they may be denied treatment based on factors such as their body mass index (BMI), age, sexual orientation or civil status, especially in the case of single women and lesbian couples. In our survey, we explicitly focused on IUI and IVF/ICSI, but there are also limits on egg and embryo donation, surrogacy, genetic testing and other technologies. Long waiting times are also a barrier to treatment in many European countries [21,25].

Specific to HIV, in all countries where MAR is on offer for people living with HIV there are limits on viral load before fertility treatment can proceed. That is, the HIV infection needs to be well managed and, in some cases, patients also have to be registered with an HIV clinic or doctor to ensure ongoing treatment. Also specific to HIV, there are intersectional, stigma-related barriers, both in society and from healthcare providers directed towards people living with HIV (see also Cane [26] on barriers and stigma). In some countries, there was a reported lack of knowledge about treatment options, among both patients and providers. Even in countries where people living with HIV can access treatment, they may hold the misconception that their HIV status precludes them from treatment. Similarly, at a clinic level, individual fertility clinics may not be aware of the most current guidelines or know where to refer patients if they cannot provide services. In the EU/EEA (including the UK) as a whole, 44% of those diagnosed with HIV in 2019 were migrants, but this ranges from nearly 0% to over 80%, depending on the host country (ECDC [27]). Migrants may not be familiar with the health system or there may be language or legal barriers to seeking treatment, particularly if their immigration status is insecure.

Individuals can also be denied treatment depending on their particular circumstances. For example, two experts in the UK independently raised the issue of reception of oocytes from the partner (ROPA). That is, donors must test negative for HIV unless oocytes are donated to a partner. However, donation between partners in a same-sex couple is not considered a 'partner donation' (HFEA [28]). In a female, same-sex, HIV-discordant couple, it would make sense for the HIV-negative partner to carry the baby to fully eliminate the risk of mother-to-child transmission (although in a planned pregnancy, with effective HIV treatment, the risk of vertical transmission is extremely low). However, in the UK, the mother living with HIV cannot 'donate' an embryo to the mother who is not living with HIV.

Feasibility of cross-border care

There are two main situations in which a patient may need to seek care abroad, funded either publicly or privately, often out of their own pocket. The first is a situation in which care is not available or allowed at home, for example a single woman or lesbian couple in Poland or a patient living with HIV in Ireland. The second situation relates to the public provision of services. For example, care is only provided in the public sector in Norway and Denmark. If a patient does not qualify for publicly funded services, or if they have been unsuccessfully treated and no longer have the right to additional rounds of IVF, they do not have the option of seeking or continuing treatment in the private sector.

In countries with a developed private sector, non-resident patients who pay for treatment themselves can access services. For example, in some countries, such as Spain and Germany, clinics that specialize in treating people living with HIV actively advertise to this patient group. However, in countries where care is primarily limited to the public sector, availability and accessibility are mixed. This is not necessarily a legal barrier but a practical one: in many European countries, public clinics do not have the capacity to take on more patients. However, in other countries, such as Belgium or the UK, fee-paying (non-resident) patients can access public clinics or clinics providing care under statutory health insurance (Table 3).

In some cases, Directive 2011/24/EU on patients' rights in cross-border healthcare or bilateral agreements may apply. Most of the countries in our study are EU member states. Under Directive 2011/24/EU on patients' rights in cross-border healthcare, patients resident in one member state can, under certain circumstances, receive planned care in another member state, reimbursed by the health and social system in their country of residence [29]. However, this is generally limited to treatments that would normally be covered in their country of residence [30]. As access to

TABLE 3 Access to cross-border care

Can a non-resident PLWH access fertility care in the following countries?		Comments
Austria	Yes	Self-financed in private clinics Restrictions on single women
Belgium	Yes	Self-financed
Denmark	No	Some exceptions
Finland	Yes	Self-financed in private clinics
France	Yes	Self-financed
Germany	Yes	Self-financed Challenges for same-sex female couples and single women depending on state
Ireland	N/a	N/a
Israel	Yes	Self-financed
Norway	No	No legal barriers but little capacity to take non-residents
Poland	Yes	Self-financed Restrictions on same-sex female couples and single women
Portugal	Yes	Self-financed in private clinics
Spain	Yes	Self-financed
Sweden	N/a	N/a
United Kingdom	Yes	Self-financed Challenges for same-sex female couples and single women depending on local authority

fertility treatments is often restricted, this does not always offer a feasible option for funding, but it remains clear how this works in practice. There are also examples of bilateral agreements between countries and regions. For example, before treatment was available in Norway, patients could be sent to Denmark for publicly funded treatment.

DISCUSSION

Policy frameworks on MAR change rapidly. In some countries, including Belgium, Denmark, Germany, Spain and the UK, MAR for people living with HIV has been available for many years. Yet, France only recently extended services to lesbian couples and single women – regardless of HIV status – and Germany is only now starting to gradually extend services to these patient groups. Conversely, in 2015 single women and lesbian couples were formally barred from services in Poland. Specific to people living with HIV, a 2012 comparison of Nordic countries found that, with the exception of Denmark, services were highly restricted for people living with HIV; today services

are also available in Finland and Norway, with only Sweden restricting access ([23,31] on Finland), although in 2017 a clinical trial on MAR for women living with HIV was launched at Karolinska University Hospital in Stockholm.

Even when treatment is allowed (or, at least, not formally banned) or explicitly listed as an entitlement, it is not always available or accessible [18,32,33,34,35]. This is the case for fertility treatment at large, and not necessarily specific to people living with HIV. For example, access to MAR in England is often referred to as a ‘postcode lottery’, indicating the disparities in which local authorities interpret national guidance regarding accessibility and availability [36,37]. Similarly, in some countries, waiting times of up to several years mean patients struggle to access publicly funded treatment [21].

There are clear parallels between the European and North American contexts. In the US, a variety of state laws around insemination limit access to treatment for people living with HIV (Gross et al. [33]). At the same time, HIV infection is considered a disability under the Americans with Disability Act (1990) such that the denial of services to people living with HIV is illegal in most cases (Gross et al. [33]; [38]). Similarly, in some European countries, such as Finland and Ukraine, discrimination legislation has been used to argue for the expansion of fertility services [31,39]. Overall, there is a need for equality/discrimination law and medical regulations to be considered and revised together, and to be regularly updated in the light of emerging medical evidence.

In the US, federal law requires separate laboratory facilities and storage tanks to reduce the risk of cross-contamination of gametes or embryos of other patients at the same clinic (Gross et al. [33]). However, similar to the European context, not all clinics in the US have the resources to implement this requirement. A survey of 140 fertility clinics in 15 US states found that more fertility clinics now offer services to people living with HIV than the previous figure of 3% which had been widely cited [18]. In Canada, a 2014 survey found that 95% of clinics responding were willing to meet HIV-positive patients for consultation, but only 50% of clinics in four provinces offered a full range of services, including IVF [34].

To this end, more research is needed on the demand and unmet need for MAR among people living with HIV. Returning to the US context, Leech et al. [18] hypothesized that ‘a misperception that only 3% of clinics in the United States offer fertility services for these couples may have impacted the physician referral rates for these services in the past and, in return, the patient demand for these services’. That is, because patients may not realize they are eligible for treatment or because healthcare providers do not know where to refer them, it may be that they do not even bother seeking care. Indeed, a study of HIV support workers in

England highlighted the importance of supporting people living with HIV in exercising their rights to treatment and in navigating complicated fertility journeys [26]. That is, even when patients were legally entitled to services, they faced barriers such as stigma, discrimination, a lack of treatment options and complicated bureaucratic systems.

CONCLUSIONS

This is the first cross-country exploration of the accessibility and availability of fertility treatment for people living with HIV in the WHO European Region. We found that in 12 out of the 14 countries mapped, MAR was provided for people living with HIV, even if there are limits to availability and accessibility. We also found that cross-border care is largely available for fee-paying patients. However, in some cases, if the destination country only, or primarily, offers services in public fertility clinics, the ability to take fee-paying patients (residents and non-residents) may be limited. Moreover, most of the policy frameworks are not unique to HIV and cover other chronic infectious diseases in general, and thus our study is also relevant to these patient groups.

However, looking more closely at these policy frameworks raises further questions. Each country has its own policy framework which can differ by region, particularly in devolved or federal systems (e.g. the UK or Germany). Laws, including EU Directives, can be interpreted in different ways and the particular nature of individual patients' situations means that people can fall through the cracks in legislation. Ultimately, more in-depth, country-level cases studies are needed. Finally, policies on paper do not always translate into practice. This is the case for fertility treatment at large, not just for people living with HIV or people with other chronic infectious diseases. Overall, more research is needed on the experiences and views of patients, health-care providers, civil society groups and policy-makers to understand the lived experiences and realities of how people living with HIV access and navigate fertility treatments.

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CONFLICT OF INTEREST

The authors declare there are no conflicts of interest.

AUTHOR CONTRIBUTIONS

The 2019 survey was designed and distributed by CB, MTA, MM and RI; this was revised and distributed by MHA and RI in 2021. The interviews were carried out by MHA, CF, AP, RI and LS. The manuscript was drafted by RI, with assistance from MHA, CF, AP and LS. All authors reviewed the final manuscript before submission.

ETHICAL APPROVAL

This research is part of a larger project which has been approved by the Swedish Ethical Review Authority and exempted from review requirements by the Committees on Health Research Ethics for the Capital Region of Denmark.

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APPENDIX 1

Interview Questions

1. Can people living with HIV legally access fertility treatment in [your country]?
2. Are there differences in access for:
 - Serodiscordant heterosexual couples (male -, female +)
 - Serodiscordant heterosexual couples (male +, female -)
 - Seroconcordant couples
 - Single females
 - Female couples?
3. If a male is living with HIV, are the following allowed:
 - Sperm washing with intrauterine insemination (IUI)
 - Sperm washing with *in vitro* fertilization (IVF) or intracytoplasmic sperm injection (ICSI)?
4. If a female is living with HIV, are the following allowed:
 - IVF and/or ICSI with partner sperm
 - IVF and/or ICSI with donor sperm
 - IUI with donor sperm
 - IUI with partner sperm?
5. How is fertility treatment funded?
 - Do people living with HIV (PLWH) have the same access as others in terms of access to funding?
6. Are there differences across regions?
 - Public/private.
6. Are you aware of the specific laws, policies and/or guidelines in your country or at EU level regarding fertility treatment for PLWH? If so, what are they?
 - Have there been any recent changes, or any planned changes that you know of?
7. Even if certain treatments are legal, do you have a sense of how often they are practised or how easily accessible they are? For example, are there a limited number of clinics in your country that offer them? Or are there long waiting times?
8. How do PLWH access information about fertility options?
9. Are you aware of clinic level barriers (dual lab setup) to treating PLWH?
10. Broadly speaking, what are barriers that PLWH face when seeking fertility treatment?
11. To what extent is cross-border care possible or feasible? For example, can a resident (living with HIV) from a different country seek fertility treatment in your country?
12. Do you have any other comments? Is there anyone else you would suggest I contact?