THE IMPERATIVE OF EQUAL ACCESS TO FERTILITY TREATMENTS ACROSS EUROPE

Fertility Europe and the European Parliamentary Forum for Sexual and Reproductive Rights White Paper

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About Fertility Europe

Fertility Europe (FE) is the European organisation representing patients' associations dedicated to (in)fertility enabling the cooperation and network of those concerned with fertility problems, patient empowerment, fertility education and advocacy for better regulations of access to fertility treatment. It was established in 2009, and currently has 31 member associations from 28 countries. FE is the patient partner organisation of the European Society for Human Reproduction and Embryology (ESHRE).

For more information, visit fertilityeurope.eu

About the European Parliamentary Forum for Sexual & Reproductive Rights

European Parliamentary Forum for Sexual & Reproductive Rights (EPF) is a network of members of parliaments from across Europe who are committed to protecting the sexual and reproductive health of the world's most vulnerable people, both at home and overseas. EPF currently has 31 Members - All Party Parliamentary Groups on Population and Development throughout the European continent. It was established in Brussels in 2000.

For more information, visit www.epfweb.org

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Glossary

ART	Assisted Reproductive Techniques
Cryopreservation	Freezing embryos to be used in the future
EBM	Evidence-Based Medicine
EIM	European IVF-Monitoring Consortium
Endometriosis	A medical condition in which the tissue lining the uterus grows outside of it
EU	European Union
ESHRE	European Society of Human Reproduction and Embryology
Fertility	The ability to conceive a child resulting in live birth
ICPD	International Conference on Population and Development
ICSI	Intracytoplasmic Sperm Injection
Infertility	Failure to achieve a pregnancy after 12 months or more of regular unprotected sexual intercourse
IRHEC	International Reproductive Health Education Cooperation
IUI	Intrauterine Insemination
IVF	In Vitro Fertilisation
MAR	Medically Assisted Reproduction
Male/Female Factor	Refers to factors that can affect fertility of men or women
OECD	Organisation for Economic Co-operation and Development
PCOS	Polycystic Ovary Syndrome
PGT-M/SR	Preimplantation Genetic Testing for Monogenic/Structural Rearrangements
SRHR	Sexual and Reproductive Health and Rights
UK	United Kingdom
UNFPA	United Nations Population Fund
WHO	World Health Organization

Executive Summary

This White Paper is a joint collaboration between Fertility Europe (FE) and the European Parliamentary Forum for Sexual & Reproductive Rights (EPF), aimed at presenting accurate and up-to-date information on infertility, its prevalence and implications as well as discrepancies in the availability of and access to fertility treatments. The White Paper also proposes necessary measures to ensure equal access to safe and efficient fertility treatments across Europe.

From a European perspective, 1 in 6 couples experiencing infertility translates to ***25 million EU citizens alone*** in need of diagnosis and treatment for infertility. Additionally, there is a group of involuntary childless people who are living without children for non-medical reasons when they deeply want to be parents. We know that this is a significant source of stress and emotional distress for those affected and can have a detrimental impact on their relationships, mental health, and overall well-being.

Having carried out an initial exploration of this topic with Fertility Europe's / EPF "European Fertility Treatments Policies Atlas", this White Paper builds on those findings and explores in depth the barriers to truly equal access to fertility treatment across Europe. Those barriers and discrepancies ought to be acknowledged and addressed to ensure that individuals and couples have equal opportunities to grow their families, regardless of their location, background and sexual orientation.

By demonstrating how the legal frameworks of European countries, including political choices, can restrict access to certain groups, the provisions of financial support and the availability of accurate education and information on fertility, the White Paper sets out 12 recommendations for European policymakers. These recommendations aim to ensure that all European citizens receive equal access to treatment, as part of their right to the highest possible level of sexual and reproductive health.

12 ways to improve equal access to safe and efficient fertility treatments - recommendations

1. Creating safe and inclusive regulations considering the rights of all parties - people who need medical help to conceive, children, donors and surrogates.
2. Guaranteeing legal access to treatment without any form of discrimination to all who need it.
3. Establishing and maintaining a legal obligation for EBM (Evidence-Based Medicine) treatments to be provided by all medical centres.
4. Providing sufficient funding for the whole range of treatments that allow people a reasonable chance to have children.
5. Implementing the best practice in legal frameworks and systemic support enabling donor-conceived children to safe ways of learning about their genetic origins.
6. Offering psychological support to deal with infertility before, during and after active treatment.
7. Maintaining regular and respectful communication of the policymakers with the patients' organisations to ensure that all legal provisions are meeting the patients' needs.
8. Including fertility as part of comprehensive sexuality education in secondary school curriculum to equip young people with knowledge.
9. Establishing public information campaigns on fertility and reproductive health at every age for every person.
10. Creating a consistent method of collecting data about infertility prevalence and involuntary childlessness.
11. Providing demographic analysis to understand and assess the impact of fertility treatment funding on society and demographics.
12. Creating a central and mandatory European register of all treatments and donations.

> Infertility has a deeply personal and heartbreaking resonance for so many Europeans. With 1 in 6 couples worldwide experiencing some form of infertility, it is long overdue to ensure that access to fertility treatments and psychological support are available to all Europeans

MEP Frances Fitzgerald (EPP, IE)

Member of the Committee on Women's Rights and Gender Equality (FEMM)

Introduction

This paper has been prepared and published to provide accurate and up-to-date information on infertility, its prevalence and implications, and discrepancies in the availability of and access to fertility treatments, as well as to propose necessary measures to ensure equal access to safe and efficient fertility treatments across Europe.

Infertility is a disease of the male or female reproductive system defined by the failure to achieve a pregnancy after 12 months or more of regular unprotected sexual intercourse. Additionally, there is a whole group of involuntarily childless people for non-medical reasons, i.e., the LGBTQAI+ community or single individuals.

Infertility is a common and growing issue. According to the latest World Health Organization report [1], around 17% of people worldwide experience infertility. It is estimated that problems in conceiving concern 1 in 6 couples of reproductive age in Europe. In some European countries, this figure reported by medical and patient associations is as high as 20%. [2] Over 25 million people in the European Union itself are affected by infertility. [3]

In response to the growing issue of infertility in Europe, medically assisted reproduction (MAR) such as in vitro fertilisation (IVF) and intrauterine insemination (IUI) have become increasingly necessary. These treatments have helped many people in Europe who otherwise would not have been able to conceive.

However, access to fertility treatments varies greatly across Europe, with some countries offering publicly funded programmes, while others rely on private insurance or out-of-pocket payment by patients. In some countries, there are inequalities depending on the region of residence or the coverage of compulsory medical insurance - limitations on the number of cycles or treatments that are covered by public health insurance or the insurance excess. [4] Many countries restrict legal access, the range of available procedures or funding for specific groups of people needing fertility treatments. Additionally, cultural, religious or other non-medical factors may influence the regulation and practice of MAR in different countries in Europe. However, it has to be stated that these restrictions and exclusions tend not to reflect society's views and changes and are often prejudices in the disguise of culture and tradition. It is therefore important to address these disparities to ensure all people have equal opportunities to expand their families. The State of World Population 2023 report [5] shows that too many people today are still unable to achieve their reproductive goals. Women's bodies should not be held captive to choices made by governments or anyone else. Family planning must not be a tool for achieving population targets, but one to empower individuals.

The right of people to decide when and how many children they want is a part of essential Sexual Reproductive and Health Rights (SRHR) and should therefore be guaranteed by the European Union to all the citizens of the Member States [6] and by policymakers in other European countries.

The European Parliament resolution of 24 June 2021 on the situation of sexual and reproductive health and rights in the EU, in the frame of women's health (2020/2215(INI)) (widely known as the Matić report) [6] addresses the full range of SRHR and highlights the importance of accessing all essential SRHR services, including comprehensive sexuality education,

contraception, abortion, maternal health and fertility services; and of preventing any form of discrimination, coercion and gender-based violence.

> The Matić report "calls on the Member States to ensure that all persons of reproductive age have access to fertility treatments, regardless of their socio-economic or marital status, gender identity or sexual orientation and stresses the importance of closely examining fertility in the EU as a public health issue, and the prevalence of infertility and subfertility which are a difficult and painful reality for many families and persons"
>
> **Paragraph 39**, (2020/2215(INI))

> Comprehensive healthcare should include full access to fertility treatments for all EU citizens, as this is one of the fundamental sexual and reproductive rights. We continuously call on Member States to ensure that all persons of reproductive age have access to fertility treatments. It is a shame that, for example, many single women and same-sex partners still do not have access to these treatments. This is a public health issue and we need to tackle it as such: comprehensively, non-discriminatory and consistently"
>
> **MEP Predrag Fred Matić** (S&D, HR)
>
> Member of the Committee on Women's Rights and Gender Equality (FEMM)

Taking into consideration all the above we find it necessary to address the following aspects in this paper:

- Definition of infertility
- Infertility prevalence
- Implications of infertility
- Infertility treatments
- Barriers and discrepancies in access to fertility treatment
- Necessary measures to ensure equal access to fertility treatments
- Recommendations

> Sexual and reproductive health and rights are the rights related to planning one's own family, the ability to have a satisfying and safe sex life, and the freedom to decide if, when, and how often to have children. These rights are particularly relevant to women's empowerment and gender equality"
>
> **Council of Europe**

Infertility

Infertility is a disease of the male or female reproductive system defined by the failure to achieve a pregnancy after 12 months or more of regular unprotected sexual intercourse. [1] Both male and female factors equally contribute to its prevalence. There are a variety of components including age, lifestyle factors such as smoking and alcohol consumption, and obesity. In addition, exposure to environmental pollutants and toxins can be directly toxic to gametes (eggs and sperm), resulting in their decreased numbers and poor quality. [7] Furthermore, underlying health conditions such as polycystic ovary syndrome (PCOS) or endometriosis for women as well as sperm quality and quantity decline for men are major contributing factors to declining infertility rates in Europe.

The WHO definition of infertility refers to it as a purely medical condition and doesn't include other aspects of involuntary childlessness, i.e., those concerning the LGBTQAI+ community or single individuals, that can be addressed by equal access to fertility treatments.

> Infertility does not discriminate: it affects about 17% of couples across the EU. In addition, there remain involuntary childless people, who despite not having medical obstacles, struggle to become parents. This is why we need to increase our efforts to ensure that all European citizens can access affordable high-quality fertility treatments

MEP Robert Biedroń (S&D, PL)

Chair of the Committee on Women's Rights and Gender Equality (FEMM)

Infertility prevalence

Infertility in the estimated 17% of the population [1] translates to 25 million EU citizens alone. Approximately 1 in 6 couples of reproductive age in Europe has problems conceiving.

Additionally, there is a group of involuntary childless people who are living without children for non-medical reasons when they deeply want to be parents. People of any age or gender can be childless-not-by-choice, due to a multitude of complex reasons. The exact figures concerning involuntary childlessness prevalence for non-medical reasons are extremely difficult to assess as individuals in this group are often off the radar of public interests or even denied the right to become parents and discriminated against for their sexual orientation or life situations, i.e., single individuals and same-sex couples etc. However, based on the practice and treatment uptake in the countries where fertility treatments are available also for these individuals, we can assume that a number of them will be interested in undergoing fertility treatments across Europe.

Therefore, new measures need to be developed to assess infertility more accurately. Fertility Europe endorses the necessity for improvement in the following areas as identified and indicated by the WHO:

- Estimate infertility prevalence by country
- Disaggregate infertility estimates by cause (male factor, female factor, both male and female factors, unexplained factors) and by age
- Develop a standard set of questions to generate consistent infertility prevalence data
- Promote and ensure consistency in definitions and measures used in infertility research. [1]

Additionally, we see the need to research involuntary childlessness occurrences for non-medical reasons and estimate its prevalence to be able to fully understand the actual need for fertility treatments.

Implications of infertility

Apart from depriving individuals of realising one of the most fundamental needs like the one of becoming a parent, infertility inflicts various collateral consequences including:

- Psychological
- Medical
- Social
- Career-related
- Financial
- Gender inequality inflicting
- Demographic and economic

Psychological and medical

Involuntary childlessness can be a significant source of stress and emotional distress for those affected and can have a detrimental impact on their relationships, mental health, and overall well-being. Typical reactions to infertility include shock, sadness, anger and frustration, loss of self-esteem and self-confidence and a general loss of sense of control. These emotions are experienced by over 80% [8] of people with infertility and many report being forever changed by the condition. Over 60% [9] reported that the infertility journey, including infertility diagnosis, consultation, treatment and pregnancy, affected their mental health. The stress of the non-fulfilment of a wish for a child has been also associated with health ramifications such as anxiety or depression. As many as 40% [8] of people facing long-term infertility reported feeling suicidal. The majority of respondents (59%) reported some detrimental impact of fertility problems and/or treatment on their relationship with their partner, while 2% of respondents reported their relationship had ended as a result. [8]

Enormous stress and related health issues deriving from infertility itself, amplified by the unknown outcome of undertaking efforts to become parents, are extremely difficult to handle. As many as 78% [8] of fertility patients declare that they would like to be offered some form of counselling. Tailored support may reduce the mental and relational impact of infertility on infertile patients and partners [9]. Psychological support should be broadly available to all who need it on their way to parenthood or to accepting life without children.

Social

The impacts of infertility are much broader than concerning only those directly affected by the condition. Close relatives and friends also bear various and complex consequences of the unintended childlessness of their loved ones. They may experience a sense of void in their families and feel deprived of playing important and positive roles in societies such as grandparents, siblings, cousins, aunts or uncles. Family relations and friendships can be jeopardised by the emotional burden and distress accompanying infertility.

Career-related

Infertility also takes its toll on one's career by decreasing professional development and capacity. Workplaces are rarely fertility-friendly and much-needed legal provisions to treat infertility and fertility treatments like other areas of reproductive healthcare, such as maternity, for instance, remain unaddressed. Without the right measures in place like entitlement to paid leave, employees dealing with infertility and undergoing fertility treatments are often forced to disclose their personal medical information or provide false reasons for their absence. In this environment, around 15% [8] of professionals opt to give up on their careers, reduce working hours or dismiss job opportunities to be able to commit fully to fertility treatments and increase their chances for parenthood. Around 58% [8] of fertility patients in the UK felt concerned that fertility treatment would affect their career prospects.

This mainly applies to women as - regardless of the actual reasons for infertility - women carry the main burden of treatment with all the consequences such as deepening gender inequalities and widening gender pay gaps.

Financial

Fertility treatments, like any advanced healthcare interventions, are costly and often out of financial reach for those who can't benefit from public funding. For many intended parents, this is an overpowering barrier resulting in involuntary childlessness for life. Others might resort to using up their savings, borrowing money or giving up on their life plans and still living beyond their financial means. The list of possible sacrifices is endless. This taken together with compromising one's career results in a vicious circle of constant financial challenges.

Gender inequality inflicting

Infertility reinforces gender inequalities. The condition has significant negative impacts on the lives of people with infertility, particularly women who are perceived as solely responsible for remaining childless in many societies. This is linked to public perception and expectations about women's role in society. Women are under constant scrutiny and enormous pressure and experience social stigma. Infertility stigma is a phenomenon related to various psychological and social tensions and is associated with a feeling of shame or secrecy. [6]

> Ensuring equal access to safe and efficient fertility treatments should be perceived as a long-term investment. Removing both financial and legal barriers to accessing those treatments could positively affect the country's demographics and economy overall

Neil Datta

Executive Director, European Parliamentary Forum for Sexual & Reproductive Rights

Demographic and economic

Concluding the topic of infertility implications, an even broader economic effect of the condition's impact must be acknowledged. Unaddressed, prolonged infertility and lack of systemic provisions for equal access to fertility treatments often result in major mental health consequences, such as anxiety or depression or even suicidal thoughts and attempts, dismissal of job opportunities or complete withdrawal from professional activities and deepening gender inequalities. Not only do the consequences of the above concern those directly dealing with infertility but also negatively affect countries' economies and demographics.

It is accepted that in countries with low infant mortality rates the replacement fertility rate is 2.1 children per woman. Achieving this level means that a population exactly replaces itself from one generation to the next. However, the fertility rate in Europe is generally well below the replacement rate. In 2022, the total fertility rate in Europe was estimated to be 1.49 births per woman (vs. 2.7 in 1950) [10] and ranging from 2.09 in Monaco to 1.2 in Malta [11] resulting in a population decline. This will have major impacts on society, the economy, tax revenues, and available manpower. The most striking feature of a low birth rate is that it will create a rising share of people over 65 and a so-called inverted population pyramid. The old-age dependency ratio for the EU was 33% on 1 January 2022 meaning that there were three people of working age per every retired person across the EU. The share of elderly people will increase and as a result, the EU's old-age dependency ratio is projected to almost double to 57.1 % by 2100. [12] This has already had profound implications for health care, government spending and tax revenues.

Ensuring equal access to safe and efficient fertility treatments should be perceived as a long-term investment. Financially assisting people with infertility in their efforts to become parents is, from a longer perspective, on many levels beneficial and profitable. What's more, funding fertility care is efficient in helping people realise their reproductive choices. [13] The ICPD Programme of Action emphasises the importance of providing access to comprehensive reproductive healthcare services, including fertility care, to individuals and couples who are seeking to have children. This approach aligns with the principle that supporting people who desire to become parents is an effective strategy. [14]

> Since we have ways to help fertility patients, the help should be available and equal to all those in need

Satu Rautakallio-Hokkanen

General Director, Fertility Europe

Infertility treatments

The growing issue of infertility and involuntary childlessness resulted in an increased need for fertility treatments. Medically Assisted Reproduction (MAR) methods, such as the ones described below, have helped many people in Europe who otherwise would not have been able to become parents.

IUI (Intrauterine Insemination) is one of the MAR methods where the best quality sperm is inserted directly into a woman's womb. This procedure can be carried out with either a partner's or a donor's sperm. The success rate depends on several factors such as the cause of infertility, the woman's age, the quality of sperm after preparation, possible ovarian stimulation etc. Still, on average, it is around 7-10% [15] per cycle. The first successful IUI recorded dates back to 1793 when John Hunter is reported to have achieved human pregnancy using IUI.

IVF (In Vitro Fertilisation) is one of the MAR methods of fertility treatment where fertilisation takes place outside of the body. During IVF, eggs are removed from the woman's ovaries and fertilised with sperm in a laboratory. The fertilised eggs, called embryos, are then transferred to the woman's womb to grow and develop. Often there are several embryos created during one IVF procedure, so some of them are cryopreserved (frozen) to be transferred later. This way one IVF treatment allows for a number of transfers enabling patients to have more chances to get pregnant or have more than one child. This whole process can be carried out using patients' own or donated eggs and sperm.

IVF has been a broadly recognised method of medically assisted reproduction for over 40 years, leading to the birth of more than 10 million children worldwide (as of January 2022) and resulting in approximately 1 million births annually. [16] Initially, it was used to treat infertility in couples with irreversible tubal issues but has since expanded to other infertility conditions, as well as for individuals who have trouble reproducing on their own, such as single women and same-sex couples. The success rate per cycle depends on several aspects such as the cause of infertility and the woman's age, where the latter is a decisive factor especially when the procedure is carried out with own eggs, and it ranges in Europe on average from around 25.1% of life birth per IVF cycle in women under 34 to 7.8 % life birth per IVF cycle in women aged over 40. [15] Over 1 million cycles are performed in Europe each year.

ICSI (IntraCytoplasmic Sperm Injection) is a type of IVF treatment that addresses severe cases of male infertility and involves drawing up a single sperm into a very fine glass needle and injecting it directly into the centre of the egg. It is usually performed because of very low sperm counts or quality where conventional IVF treatment will be unlikely to succeed because fertilisation will probably not occur. In cases when sperm is not present in the ejaculate, sperm can be taken directly from the testicle or surrounding tubes as well. ICSI is at least as successful as standard IVF.

PGT-M/SR - preimplantation genetic testing of embryos, formerly known as Preimplantation Genetic Diagnosis. This is a special type of IVF which helps couples who are at risk of having a child with a serious genetic condition. Embryos are created outside of the body and are tested for the genetic condition in the family. This could be a genetic condition caused by one gene or a chromosomal structural rearrangement. Only embryos which are not affected by the genetic condition are transferred into the womb.

Donation is a form of third-party reproduction in which gametes and/or embryos used in treatment originate from donors. It is an option for people who, for various reasons don't use their own gametes in fertility treatment, for example, they don't produce their own gametes or have undergone a number of unsuccessful treatments or are carriers of severe genetic mutations or diseases, same-sex couples or single people etc. There are various forms of donations, i.e., egg donation, sperm donation, double donation (simultaneous egg and sperm donation) and embryo donation. Egg and embryo donations always involve a form of IVF treatment while donated sperm can be also used in IUI treatment.

European countries regulate donation in 3 different ways: strictly anonymous (where a donor remains unknown to the parents and a child), non-anonymous donations (where donors' identity may be disclosed to a donor-conceived child once they reach adulthood) or mixed (where patients can choose between anonymous or non-anonymous donation).

Testimonials of donor-conceived people [17] demanding their right to know their genetic origins as well as psychological research made several European countries change their legislation to grant non-anonymous donations. In addition, the wide availability of genetic testing combined with the above evidence should make policymakers realise that donors' anonymity cannot be guaranteed anymore and also for this reason anonymous donation should be banned in favour of non-anonymous donation. Public education on donation and counselling for donors and patients should complement the legal change. The ramifications and potential psychosocial consequences for all involved should be made clear already at the first consultation. Donors, patients and subsequent donor-conceived children should be provided with necessary information and counselling before, during and after donation. [18]

> Anonymity should be waived for all future gamete donations in Council of Europe member States, and the use of anonymously donated sperm and oocytes should be prohibited
>
> **Council of Europe**

Another aspect is quotas for the number of patients that can be treated with a single donor, or the maximum number of children born or families grown from a single donor. The international distribution of donors' gametes and the travelling of intended parents and donors should be recorded in the European registers and the quotas should be defined and implemented in the legal framework.

Surrogacy is when a woman carries a baby for a couple or individual who are unable to conceive or carry a child themselves for medical, biological, physical or psychological reasons. The intended parent(s) are the person(s) who become the legal parent(s) of a child born through surrogacy. There are two types of surrogacies, traditional surrogacy and host/gestational surrogacy. Traditional surrogacy is a pregnancy where the surrogate is genetically related to the baby and becomes pregnant through IUI. While this used to be common, most surrogacy arrangements today involve host/gestational surrogacy. Host/gestational surrogacy is when IVF is used, either with the eggs of the intended mother or with donor eggs. The surrogate mother, therefore, does not use her own eggs and is genetically unrelated to the baby.

Surrogacy is one of the least available and most poorly regulated treatments in Europe. Only a handful of countries across the continent offer surrogacy, mainly commercial. Due to a lack of alternatives those countries have become the last resort intended parents opt for despite encountering ethical reservations or risking legal barriers in bringing their babies back to their home countries or obtaining citizenship for them. An example of a country in Europe with comprehensive legal provisions (currently under revision) for altruistic surrogacy is the United Kingdom. They guarantee the safety and well-being of all engaged, i.e., surrogates, intended parents and children born through surrogacy, and secure their rights. The collation of these two legal and factual realities shows clearly that thorough regulations are needed to protect surrogates, intended parents and children born through surrogacy from potential exploitation or coercion as well as to secure their rights.

Fertility preservation is the process of saving or protecting eggs, sperm, or reproductive tissue so that a person can use them to have children in the future. All patients of reproductive age scheduled to undergo gonadotoxic treatment should be referred to the fertility preservation team for information, counselling and, if relevant, reimbursed fertility preservation treatment. Similarly, transgender people should be informed about fertility issues and fertility preservation options before starting hormonal treatments.

> Infertility prevalence is similar all over Europe. Equal access to infertility treatments should follow the same pattern

Carlos Calhaz-Jorge

Chair, European Society of Human Reproduction and Embryology

> Government policies could mitigate the many inequities in access to safe and effective fertility care. To effectively address infertility, health policies need to recognize that infertility is a disease that can often be prevented, thereby mitigating the need for costly and poorly accessible treatments. [...] In addition, enabling laws and policies that regulate third-party reproduction and ART are essential to ensure universal access without discrimination and to protect and promote the human rights of all parties involved. Once fertility policies are in place, it is essential to ensure that their implementation is monitored, and the quality of services is continually improved

World Health Organisation

Barriers and discrepancies in access to fertility treatments

Access to fertility treatment in European countries is not equal. These discrepancies must be acknowledged and addressed to ensure that individuals and couples have equal opportunities to grow their families, regardless of their location, background and sexual orientation.

Equal access to treatment can be defined by meeting all of the following conditions together:

- Providing a comprehensive and inclusive legal framework in which the whole range of safe and efficient fertility treatments is made legally available and free from all forms of discrimination, coercion or exploitation for all involved
- Providing the actual availability of the whole range of treatments
- Securing financing of the whole range of fertility treatments by creating necessary provisions and then allocating sufficient funding

The legal regulations and funding systems for fertility treatments are diverse and fragmented in Europe and hard to understand, so it is important that there is a tool to present and compare the data enabling citizens to see what they should expect from their policymakers and care providers and for the politicians to be informed about the unmet patients' needs in their countries.

There are differences in the legal and regulatory frameworks surrounding fertility treatment in different European countries. For example, some countries may have restrictions on certain types of fertility treatments, such as surrogacy or egg donation or may exclude some specific groups of people as not eligible for treatment, i.e., same-sex couples and single individuals.

The availability and types of fertility treatments can vary widely depending on the country and the healthcare system in place. In general, fertility treatments are more readily available in countries with a comprehensive healthcare system and greater government support for reproductive rights.

For example, countries such as Denmark and Belgium have highly developed and well-funded healthcare systems, which provide access to fertility treatments to all citizens without discrimination. In these countries, a high proportion of the population is covered by public health insurance, which covers most of the costs associated with fertility treatments.

On the other hand, in countries with less developed healthcare systems, such as some of the countries in Eastern Europe, access to fertility treatment can be more limited. In these countries, patients may have to pay out-of-pocket for fertility treatment, which can be prohibitively expensive for many people.

> It is our responsibility as MAR professionals to raise attention to treatment disparities across Europe and fight for equal access to reproductive medicine
>
> **Cristina Magli**
>
> Immediate Past Chair, European Society of Human Reproduction and Embryology

Necessary measures to ensure equal access to fertility treatments

To define what should be the legal framework for access to fertility treatments our expert group analysed the data available from 'The Survey on ART and IUI: legislation, regulation, funding and registries in European countries: The European IVF-monitoring Consortium (EIM) for the European Society of Human Reproduction and Embryology (ESHRE)' [4] and created "European Fertility Treatments Policies Atlas" [19]. The Atlas is a comparative map that scores 43 countries and territories on equal access to safe and efficient fertility treatments.

The Atlas focuses on 3 criteria and 22 sub-criteria:

- Legal regulations
- Funding/reimbursement and
- Patients perspective

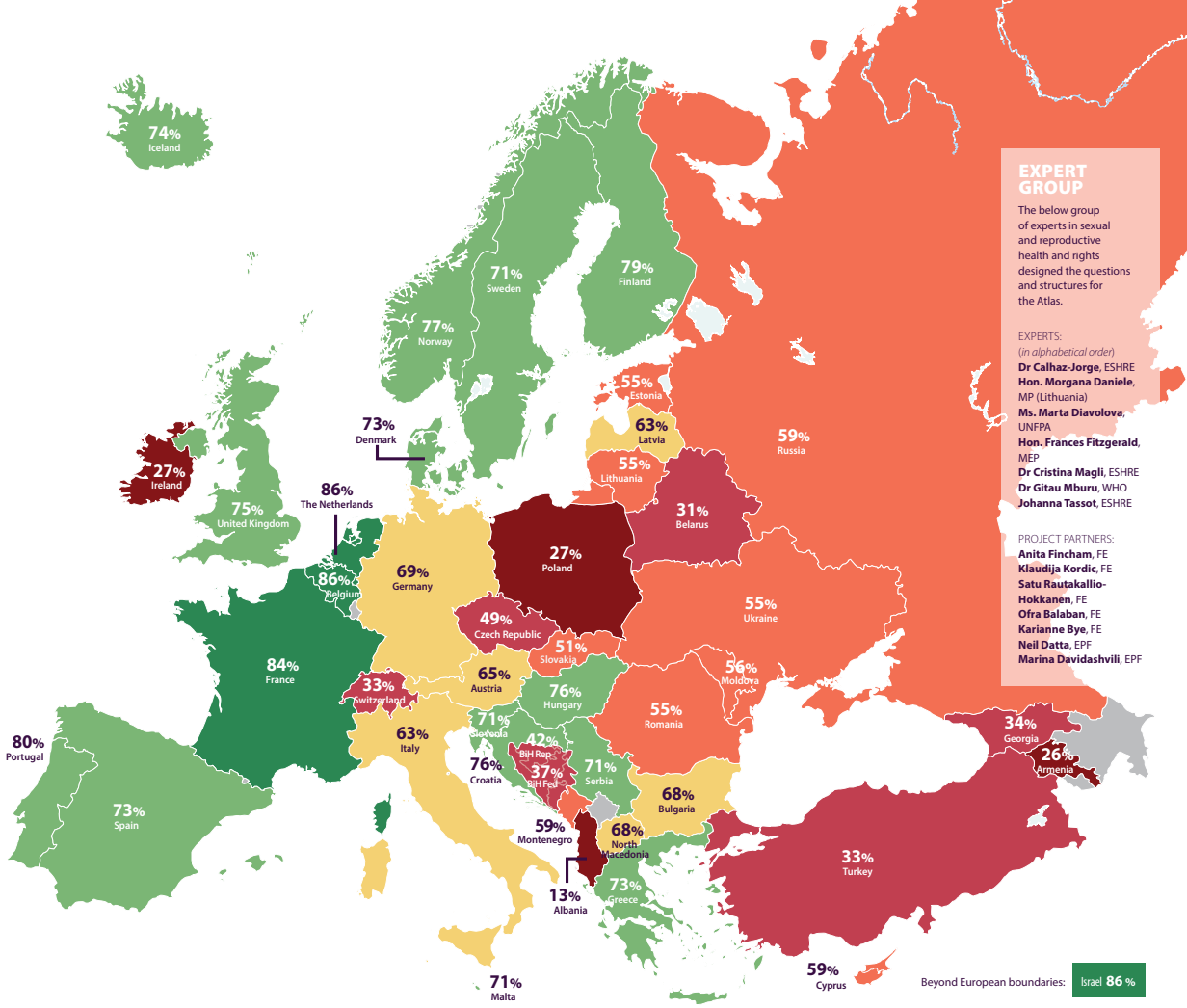
Based on the selected criteria experts defined the PERFECT COUNTRY for patients to access fertility treatments:

- Dedicated MAR law providing a legal framework for the stability of access to treatment
- National registers of treatments and donors funded by the state
- Access to treatment and donor treatment to all who need it with sufficient public funding
- Access to funded genetic testing of embryos for serious diseases
- Non-anonymous donation with the identity of donors revealed to children
- Full funding for fertility treatment across the whole country
- Psychological support as part of funded fertility treatment
- Policymakers consult patients associations on legal frameworks
- State-organised and funded fertility education at schools.

The findings of Atlas showed a very fragmented picture of access to treatments in Europe.

RANKING POINTS SCALE

Belgium	86 %
Israel	86 %
The Netherlands	86 %
France	84 %
Portugal	80 %
Finland	79 %
Norway	77 %
Croatia	76 %
Hungary	76 %
United Kingdom	75 %
Iceland	74 %
Denmark	73 %
Greece	73 %
Spain	73 %
Malta	71 %
Serbia	71 %
Slovenia	71 %
Sweden	71 %
Germany	69 %
Bulgaria	68 %
North Macedonia	68 %
Austria	65 %
Italy	63 %
Latvia	63 %
Cyprus	59 %
Montenegro	59 %
Russia	59 %
Moldova	56 %
Estonia	55 %
Lithuania	55 %
Romania	55 %
Ukraine	55 %
Slovakia	51 %
Czech Repbulic	49 %
Bosnia & Hercegovina - Rep	42 %
Bosnia & Hercegovina - Fed	37 %
Georgia	34 %
Switzerland	33 %
Turkey	33 %
Belarus	31 %
Ireland	27 %
Poland	27 %
Armenia	26 %
Albania	13 %



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TIME FOR A EUROPEAN GAME-CHANGING MOVEMENT ON INFERTILITY

In the European Union alone **25 million citizens face infertility**

Infertility affects **1 in 6 couples worldwide**

WE CALL ON POLICY MAKERS TO:

1. **Recognise** the right to try to have a child as a universal right across the EU;
2. **Ensure** equal, fair and safe access to fertility treatments;
3. **Provide** public funding for all lines of fertility treatments;
4. **Engage** the public sector in providing better information about fertility and infertility;
5. **Implement** communication campaigns to remove the stigma associated with infertility.

JOIN OUR CALL TO ACTION AT HTTPS://FERTILITYEUROPE.EU/CTA/

INTERNATIONAL GUIDELINES

EUROPEAN PARLIAMENT

Notes that infertility is a medical condition recognised by World Health Organization that can have severe effects such as depression; points out that infertility is on the increase and now occurs in about 15 % of couples; calls on the Member States, therefore, to ensure the right of couples to universal access to infertility treatment[1];

Calls on the Member States to ensure that all persons of reproductive age have access to fertility treatments, regardless of their socio-economic or marital status, gender identity or sexual orientation; stresses the importance of closely examining fertility in the EU as a public health issue, and the prevalence of infertility and subfertility which are a difficult and painful reality for many families and persons; calls on the Member States to take a holistic, rights-based, inclusive and non-discriminatory approach to fertility, including measures to prevent infertility, and ensuring equality of access to services for all persons of reproductive age, and to make medically assisted reproduction available and accessible in Europe[2].

WORLD HEALTH ORGANISATION

Government policies could mitigate the many inequities in access to safe and effective fertility care[3].

[1] EP Para 26 of the European Parliament resolution on the demographic future of Europe (2007/2156 (INI))
[2] EP Para 39 of the European Parliament Resolution on the situation of sexual and reproductive health and rights in the EU, in the frame of women's health(2020/2215(INI))
[3] WHO https://www.who.int/news-room/fact-sheets/detail/infertility

Who is behind the Atlas?

This initiative is powered by Fertility Europe (FE) and the European Parliamentary Forum for Sexual and Reproductive Rights (EPF). We are grateful to ESHRE EIM Survey on ART and IUI and to the numerous national organisations and country experts who contributed to gathering the data presented in the Atlas. The Atlas was produced in partnership with a group of experts in reproductive health (see above) who designed the questions and structures. The scope and the content of the European Atlas of Fertility Treatment Policies is the sole responsibility of FE (contact: office@fertilityeurope.eu) and EPF (contact: secretariat@epfweb.org).

Legal situation

- 38 countries have MAR law (Medically Assisted Reproduction)
- 33 countries have national registers of MAR activity
- 16 countries have donor register

Legally available treatments

- 43 countries (all) provide IVF / ICSI with own gametes to heterosexual couples
- 41 countries provide IVF / ICSI with sperm donation to heterosexual couples (ICSI - Intracytoplasmic Sperm Injection)
- 20 countries provide IVF / ICSI with sperm donation to female couples
- 32 countries provide IVF / ICSI with sperm donation to single women
- 40 countries provide IVF / ICSI with egg donation to heterosexual couples
- 17 countries provide IVF / ICSI with egg donation to female couples
- 7 countries provide IVF / ICSI with egg donation to male couples
- 25 countries provide IVF / ICSI with egg donations to single women

Legal framework

The ideal legal framework should be comprehensive and inclusive and create provisions for the whole range of fertility treatments for all individuals without discrimination based on sexual orientation, ethnicity, gender or life situations etc. The whole range of fertility treatments should be regulated in a way to guarantee the efficacy, safety and well-being of all involved, i.e., patients, donors, surrogates and children born through MAR methods as well as their siblings and half-siblings, in both the genetic and social meaning of the words. The regulations should observe and secure their rights and prevent any form of exploitation or coercion before, during and after fertility treatments. The especially vulnerable individuals, such as children born thanks to fertility treatments, surrogates and donors should be able to benefit from enforced protection.

The needs and life goals of potential and intended parents should be acknowledged and accommodated in a broad interdisciplinary aspect of medical and socio-economic care. The expectation that the need for personal development or having children later in life can be ignored and that people's lives can be arbitrarily shaped by governments can't be justified. Furthermore, the attempts to do so proved ineffective, although this approach seems to be present in regulations and demographic policies across Europe.

Implementing excessively restrictive or exclusive laws only appears to refrain people from opting for desired treatments. In the best scenario, they can seek fertility treatments elsewhere but in the far less optimistic case, they can resort to undertaking potentially risky or harmful behaviours. Travelling to another region for fertility treatment is already associated with an increased risk of health dangers for mothers and their potential newborns [20] and can result in an increased economic burden on the public healthcare and judicial systems.

Policymakers should never ignore these potential ramifications or what's more create provisions for them to potentially occur when introducing legal solutions.

In addition to the above, associations of patients and fertility professionals at European and national levels should create, implement and execute a code of practice to provide healthcare professionals with a practical guide on how to comply with legal and ethical requirements and achieve the highest standard of care and the proper approach to patients' needs.

Crucial in all sorts of policymaking is maintaining regular and respectful communication with the patients' representatives to ensure that all legal changes are meeting patients' needs.

> The number of people having access to reimbursed fertility treatments and the right to try to have a child is far from the real needs in Europe. Therefore, equal access to publicly funded fertility treatments is imperative for Europe today and its future
>
> **Klaudija Kordić**
> Chair, Fertility Europe

Funding

Funding fertility treatments is a crucial step towards recognising infertility as a disease and involuntary childlessness in general as a phenomenon with vast implications, and for providing due health care for all who need it. Therefore, it is vital not only to have legal provisions for funding in place but also to allocate sufficient funds for that purpose.

Fertility treatment funding:

- Improves public perception of infertility
- Improves public perception of fertility treatments
- Raises awareness of the infertility burden
- Removes financial discrimination against infertility patients

Unfortunately, funding of fertility treatment in Europe is very diverse - from unlimited in Israel and Serbia, through generous in Belgium, France and Finland, to non-existent in Poland, Ireland (where it is under legal proceedings) and Armenia.

Systemic lack of funding puts those needing costly fertility treatment, already stressed and exhausted, in the distressing situation of gathering funds that are often beyond their reach. They become customers of fertility clinics selling dreams with uncertain results, often abroad. All this takes place while they are paying mandatory national health insurance in their own country where they should be guaranteed access to health care.

> We welcome Fertility Europe's and the European Parliamentary Forum for Sexual and Reproductive Rights' White Paper, as it resonates deeply with our shared vision. It serves as a reminder of the crucial need to prioritise access to information and support for all patients, on their unique fertility path

Anca Toma

Executive Director, European Patients' Forum

Access to information

This generation of infertility patients is learning about their fertility in a tough way - they are not provided with education on fertility and its limitations. They were left with no education or advice on modifiable (lifestyle) factors influencing fertility and they were left to learn about it from the media focusing on the extreme stories of celebrities having children very late in life.

Research shows that people's knowledge about fertility and what they can do to improve the chance of having children is low. For people who want to have children, more awareness about the factors that affect fertility and the probability of pregnancy might improve their chances of achieving their desired family size. As both female and male fertility decline with age, there is a greater risk of people having fewer children than they planned or staying childless, even after fertility treatments. The Organisation for Economic Co-operation and Development (OECD) states the average rate of childlessness among women at the end of the reproductive period is 18% among women born in 1970 [21] and some of it is involuntary childlessness due to infertility or personal circumstances.

If and when people have children is influenced not only by their desires and personal circumstances but also by social and economic factors. Also, most people overestimate the chance of achieving parenthood through IVF and this might lead to unrealistic expectations of what is possible with IVF [22]. Improved public awareness about the potentially modifiable factors that affect fertility could reduce the risk of infertility and the need for infertility treatment. This evidence shows that public education initiatives are needed to help people who want to have children make informed reproductive decisions to achieve their desired family size and have healthy babies.

We need age-appropriate fertility education at schools, so young people can be equipped with knowledge allowing them to make informed decisions about their future and their families. There is also an urgent need for systemic and consistent public information that is medically accurate and prepared in the spirit of respecting everybody's sexual and reproductive health choices.

We can see an effective role for the reproductive health specialists and fertility clinics to educate by providing patients and the general public with EBM (evidence-based medicine) information about the efficacy of the offered treatments and success rates as reported to the national and European MAR registers.

The call for universal fertility education was also part of Fertility Europe's 2019 Call to Action to encourage politicians to support equal access to infertility treatment and education in Europe. The IRHEC (International Reproductive Health Education Cooperation) founders, in collaboration with members of Fertility Europe and ESHRE, developed a fertility education poster, which was launched in the EU Parliament as part of the 'My Fertility, My Future, My Family' campaign organized by Fertility Europe during their annual European Fertility Week in 2019. The poster targets the general public of all ages, to facilitate the conversation around fertility education.

> Bias and discrimination in Europe may be presented as 'tradition' or 'culture' but stand in the way of the effective legal frameworks needed to provide comprehensive education and equal access to safe and efficient treatments to all who need them. Including patients' organisations is essential to address patients' real needs and for a constructive policymaking process

Anita Fincham

Advocacy Manager, Fertility Europe

Recommendations

As presented in this paper, the current legal framework and practice in access to fertility treatment are insufficient, fragmented and often discriminatory. What's more, it doesn't provide the essential measures guaranteeing the safety and well-being of all concerned. Far too often fertility, infertility and fertility treatments are not seen as integral parts of Sexual Reproductive and Health Rights. As a result, patients and other involuntary childless people are not offered necessary health care. The following are our recommendations to urgently introduce the needed changes.

12 ways to improve equal access to safe and efficient fertility treatments - recommendations

1. Creating safe and inclusive regulations considering the rights of all parties - people who need medical help to conceive, children, donors and surrogates.
2. Guaranteeing legal access to treatment without any form of discrimination to all who need it.
3. Establishing and maintaining a legal obligation for EBM (Evidence-Based Medicine) treatments to be provided by all medical centres.
4. Providing sufficient funding for the whole range of treatments that allow people a reasonable chance to have children.
5. Implementing the best practice in legal frameworks and systemic support enabling donor-conceived children to safe ways of learning about their genetic origins.
6. Offering psychological support to deal with infertility before, during and after active treatment.
7. Maintaining regular and respectful communication of the policymakers with the patients' organisations to ensure that all legal provisions are meeting the patients' needs.
8. Including fertility as part of comprehensive sexuality education in secondary school curriculum to equip young people with knowledge.
9. Establishing public information campaigns on fertility and reproductive health at every age for every person.
10. Creating a consistent method of collecting data about infertility prevalence and involuntary childlessness.
11. Providing demographic analysis to understand and assess the impact of fertility treatment funding on society and demographics.
12. Creating a central and mandatory European register of all treatments and donations.

Conclusions

Growing numbers of Europeans of reproductive age are struggling to conceive when they want to have children. They have never been provided with fertility and comprehensive sexuality education, they are living under the stress of not having social security of housing or jobs. They were left to popular culture to make them believe that they can have children much later in life. Infertility seriously increases the risk of depression and other mental health issues. According to patients and people of reproductive age, there is still a stigma around infertility and fertility treatments in many countries, especially those where access to treatment is limited or not funded. Numerous international documents have called on governments to ensure access to sexual and reproductive health including fertility care and to support couples and individuals wishing to have children.

We advocate for European policymakers to respect the right of people to decide when and how many children they want. State-funded fertility education at schools and public information campaigns are needed to help people make informed choices about their family situation. The right of patients to access publicly funded EBM therapies when they need them should be secured and protected. This is a fundamental Sexual and Reproductive Health Right and therefore needs to be guaranteed by the European governments to all individuals.

https://fertilityeurope.eu/cta/

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