

EUROPEAN POLICY AUDIT ON FERTILITY (EPAF)





Satu Rautakallio-Hokkanen

Chair

Fertility Europe




ABOUT FERTILITY EUROPE

Main goals:

-  Build a strong cross border network amongst European patients
-  Share best practices
-  Promote social change regarding the perception of infertility
-  Promote education in the field of reproductive health care

ABOUT FERTILITY EUROPE

We promote:

-  Patient empowerment
-  The fight against health inequalities and discrimination
-  The support of quality care, patient safety and patient centered treatments
-  The development of ethical guidelines and regulations within each European country

ABOUT FERTILITY EUROPE

Our achievements:

- ☺ Meetings with national officials
- ☺ Written statements of support
- ☺ Published policies
- ☺ Published statements about infertility

FERTILITY EUROPE MEMBERS

24 members in 22 countries

De Verdwaalde Ooievaar Netwerk
Fertiliteit/**BELGIUM**

Iskambebe/**BULGARIA**

Sdruzhenie Zachatie/**BULGARIA**

Association Roda/**CROATIA**

Adam/**CZECH REPUBLIC**

Lapsettomien yhdistys Simpukka/**FINLAND**

Maia/**FRANCE**

Magna Mater/**GREECE**

Kiveli/**GREECE**

Tilvera/**ICELAND**

National Infertility Support & Information
Group/**IRELAND**

Chen/**ISRAEL**

Amica Cicogna/**ITALY**

Malta Infertility Network/**MALTA**

Nas San/**MONTENEGRO**

Freya/**THE NETHERLANDS**

Ønskebarn/**NORWAY**

Nasz Bocian/**POLAND**

Associação Portuguesa de
Fertilidade/**PORTUGAL**

Asociatia SOS Infertilitatea/**ROMANIA**

Sansa za roditeljstvo/**SERBIA**

Barnlängtan/**SWEDEN**

Fertility Network UK/**UNITED KINGDOM**

Çider/**TURKEY**

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EUROPEAN FERTILITY WEEK (EFW)

#fertilitymatters
#40reasons

REASON #1
#40REASONS

EUROPEAN FERTILITY WEEK

Europe needs young people to keep its regions prosperous and take care of the elderly.

REASON #9
#40REASONS

EUROPEAN FERTILITY WEEK

In Nordic countries, children born with the help of fertility treatments account for about 6-8% of all children born.

REASON #37
#40REASONS

EUROPEAN FERTILITY WEEK

Infertility impacts as many as 186 million people worldwide.

REASON #13
#40REASONS

EUROPEAN FERTILITY WEEK

The World Health Organisation recognises infertility as a medical condition.

REASON #25
#40REASONS

EUROPEAN FERTILITY WEEK

Many of those who struggle with infertility report feeling forever changed by the experience.

REASON #4
#40REASONS

EUROPEAN FERTILITY WEEK

IVF has resulted in the birth of over 6.5 million people.

REASON #28
#40REASONS

EUROPEAN FERTILITY WEEK

As a man ages, his chances of conceiving and having a healthy child decline.

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INFERTILITY IN EUROPE

- 25 million people face difficulties in conceiving in Europe
- One in six/five people in their reproductive age



WHO's DEFINITION OF INFERTILITY

World Health Organisation defines:

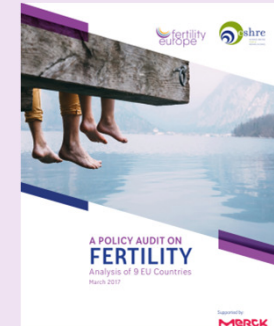
"infertility is a disease of the reproductive system defined by the failure to achieve a clinical pregnancy after 12 months"

...

"it is the choice of each individual and couple, within their own sense of conscience, to determine if they intend pregnancy, and if so, the size of their family unit and the timing of when to have a child or children".

EUROPEAN POLICY AUDIT ON FERTILITY

- 🌈 Joint project of Fertility Europe and ESHRE
- 🌈 Started in 2016
- 🌈 An overview of key facts and statistics related to fertility
- 🌈 Includes a detailed overview of policies and regulations in 9 EU member states
- 🌈 An effective and simple communication tool that patient groups, healthcare professionals and interested health advocates can use



EUROPEAN POLICY AUDIT ON FERTILITY

Country selection was to ensure a meaningful and balanced geographical scope of analysis.

The 9 countries chosen were:

The Czech Republic



France



Germany



Italy



Poland



Romania



Spain



Sweden



United Kingdom



EUROPEAN POLICY AUDIT ON FERTILITY

Main areas of interest:

- 🌈 Key Facts and Figures
- 🌈 Infertility Policies
- 🌈 Screening and diagnosis
- 🌈 Treatment and reimbursement / state funding
- 🌈 Awareness raising activities
- 🌈 Future outlook

EUROPEAN POLICY AUDIT ON FERTILITY

**CZECH
REPUBLIC**

FRANCE

GERMANY

ITALY

POLAND

ROMANIA

SPAIN

SWEDEN

UNITED
KINGDOM

Key Facts and Figures:

- ☺ Mean age of woman at the first childbirth: 29.9 years

Treatment and Reimbursement / State Funding:

- ☺ Wide variety of treatments available
- ☺ reimbursement of fertility treatments is 100 % for up to 4 cycles IVF and six IUI for women aged 22-39 years.

There is a law about Medically Assisted Reproduction (MAR).

Future outlook:

- ☺ A new "Family Policy" is under development.
- ☺ Request that the state increases its financial support of MAR and broader accessibility.

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Key Facts and Figures:

- ☺ Mean age of woman at the first childbirth is 30.3 years

Treatment and Reimbursement / State Funding:

- ☺ A wide variety of treatments available
- ☺ 100 % coverage for women under 43 years including 4 IVF treatments and up to six IUI treatments.

Access to MAR is regulated under the 1994 ethichs law including 3 other laws.

Future outlook:

- ☺ Increasing interest in the cause of male infertility
- ☺ Recent debates around access to MAR for same sex couples called into question the need to increase access in general.

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Key Facts and Figures:

Mean age of woman at the first childbirth is 30.9 years

Treatment and Reimbursement / State funding:

- 🌈 Egg donation and surrogacy not allowed.
- 🌈 Embryo freezing possible only under certain circumstances as an emergency measure.
- 🌈 Statutory health insurances reimburse 50 % of the first 3-4 attempts and some federal states provide 25 % respectively of the remaining 50 % of private contributions.
- 🌈 These conditions applicable only to married couples.

“Embryo protection act” and regional guidelines for reproductive treatment regulate access to MAR.

Future outlook:

- 🌈 Patient organisations petitioning for an amendment to the “Embryo Protection Act” to allow access to egg donation and surrogacy as well as improved access to embryo freezing, PGD and PGS.

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Key Facts and Figures:

- ☺ Mean age of woman at the first childbirth is 31.8 years

Treatment and Reimbursement / State funding:

- ☺ Donor gametes allowed, surrogacy not available.
- ☺ Access to MAR treatments only available upon presentation of a 'Certification of Infertility'
- ☺ Funding varies between regions, however, IVF is generally covered at 65 %

MAR is regulated by law

Future outlook:

- ☺ In July 2016 the Ministry of Health reformed the basket of publically funded healthcare services to include all fertility treatments to ensure consistency across the country.
- ☺ Revised list of health services covered under the public health system was published on 12th of January 2017 and is expected to, over time, equalise regional differences in treatment access.

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Key Facts and Figures:

- ☺ Mean age of woman at the first childbirth is 29.1 years

Treatment and Reimbursement / State funding:

- ☺ No reimbursement / state funding for MAR treatments but some basic screening examinations are covered.

“Infertility Treatment” legislation entered into force in 2015 and according to one of its articles, embryo donation is compulsory in some cases.

Future outlook:

- ☺ There are social and bioethical debates in Poland about infertility treatments characterised for example by stigma and family pressure. A number of attempts to amend the legislation have been made to stop IVF treatments in Poland.

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Key Facts and Figures:

- ☺ Mean age of woman at the first childbirth is 29.9 years

Treatment and Reimbursement / State funding:

- ☺ IVF and embryo transfer are the only partially funded treatment options.
- ☺ Couples must meet certain eligibility criteria
- ☺ No cover of medical exams nor medication

There is no specific law regulating MAR.

Future outlook:

- ☺ Draft MAR legislation is currently under discussion.

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Key Facts and Figures:

- Mean age of woman at the first childbirth is 31.8 years

Treatment and Reimbursement / State funding:

- treatments are state funded for therapeutic purposes (e.g. individuals diagnosed as infertile due to medical condition(s) or if hereditary diseases are suspected to impact the pregnancy or child).
- Treatment reimbursement schemes differ by regional community.

MAR is addressed under the "National law 35/1988".

Future outlook:

- National debate remains active around patient choice and reproductive rights. Although this is a social debate, it has influence on access and availability of MAR treatments.

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Key Facts and Figures:

- ☺ Mean age of woman at the first childbirth is 31 years.

Treatment and Reimbursement / State funding:

- ☺ Almost complete coverage within public healthcare system: six IUI treatments and 3 IVF treatments.
- ☺ There are regional variations in access to MAR treatments, especially with regards to wait times and psychological counselling availability.

In 2014, the Swedish Association of Local Authorities and Regions published a “Nationwide Infertility Recommendation”, which outlines the national policies for MAR.

Future outlook:

- ☺ A proposed change to the legislation is currently under review including for example the freezing time of embryos, double gamete donation and surrogacy.

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Key Facts and Figures:

- ☺ Mean age of woman at the first childbirth is 30.2 years

Treatment and Reimbursement / State funding:

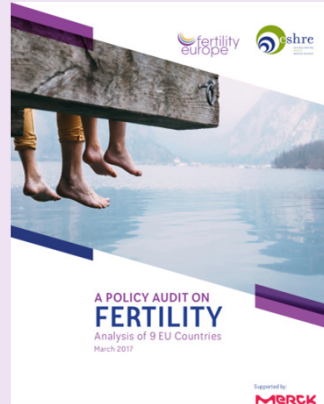
- ☺ Consistent state funding of treatments in Scotland, Wales and Northern Ireland but in England the funding varies by region.

While there are no legislative acts or strategies that reference an individual's right to infertility treatment, there are also no legal restrictions to the availability of MAR based on marital status or sexual orientation.

Future outlook:

- ☺ Unfortunately it is expected state funded treatment to become increasingly difficult in the coming years. Brexit also poses uncertainty for UK patients in being able to work closely with patients from other EU members states on common objectives.

EUROPEAN POLICY AUDIT ON FERTILITY



DOWNLOADED HERE:

WWW.FERTILITYEUROPE.EU



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EUROPEAN POLICY AUDIT ON FERTILITY: KEY FINDINGS

HEALTH LITERACY, STIGMA AND TABOOS

- 🌈 Limited information and education on infertility (all countries)
- 🌈 Infertility and fertility protection underestimated and misunderstood
- 🌈 Awareness campaigns mainly by patient groups and health professionals, few governmental
- 🌈 Stigma and taboos: infertility is seen as a social rather than medical condition

EUROPEAN POLICY AUDIT ON FERTILITY: KEY FINDINGS

INFERTILITY LEGISLATION

- ☺ All 9 had legislation governing MAR – independently or part of other legislative framework
- ☺ Treatment eligibility criteria (age, sexual orientation, marital status) differ significantly
- ☺ Two countries (Czech republic and Spain) rank among highest in Europe for infertility treatments to non-nationals

EUROPEAN POLICY AUDIT ON FERTILITY: KEY FINDINGS

TREATMENT: ACCESS AND REIMBURSEMENT/FUNDING

- 🌈 Availability differs across these countries
- 🌈 Czech Republic and UK have the largest number of options available
- 🌈 Some countries restrict the availability of some treatments with rules, conditions and structures
- 🌈 All recommend psychological counselling

EUROPEAN POLICY AUDIT ON FERTILITY: KEY FINDINGS

REIMBURSEMENT/STATE FUNDING

- 🌈 Variety of biological factors determine eligibility for treatments with age as the common criteria in all 9 countries
- 🌈 In Italy and Spain a medical certificate is required
- 🌈 IVF the first line of treatment although reimbursements are at various levels
- 🌈 Regional variations in state funded MAR in some countries
- 🌈 Political priorities and public attitudes determin scope and availability

EUROPEAN POLICY AUDIT ON FERTILITY: THE PATIENT PERSPECTIVE




ACCESS TO TREATMENTS AND THE LACK OF IT

Access limitations:

- 🌈 Availability of treatments and/or medical procedures
- 🌈 Eligibility criteria either for treatment as such or for funding
- 🌈 Funding and reimbursement
- 🌈 Excluding certain procedures
- 🌈 Regional disparities

EUROPEAN POLICY AUDIT ON FERTILITY: THE PATIENT PERSPECTIVE

When IS the limited access to treatments justified?

-  When it's not safe
-  When it's not efficient
-  When it's not fair




EUROPEAN POLICY AUDIT ON FERTILITY: THE PATIENT PERSPECTIVE

When is the limited access to treatments NOT justified?

- ☺ When it IS safe
- ☺ When it IS efficient
- ☺ When it IS fair
- ☺ If justified with discrimination against sexual orientation, life choices or ideology

EUROPEAN POLICY AUDIT ON FERTILITY: THE PATIENT PERSPECTIVE

Consequences of limitations?

-  Medical tourism
-  Risky decisions
-  Risk of exploitation

EUROPEAN POLICY AUDIT ON FERTILITY: THE PATIENT PERSPECTIVE

Price of limitations?

- 🌈 Perpetuating stigma
- 🌈 Lack of understanding
- 🌈 Taboos
- 🌈 Compromising safety and fairness
- 🌈 Lack of control

EUROPEAN POLICY AUDIT ON FERTILITY: THE PATIENT PERSPECTIVE

What can be done?

- 🌈 Recognize the existing need and follow it
- 🌈 Do not ignore the current world
- 🌈 Be inclusive, not exclusive
- 🌈 Concentrate on how, not on who
- 🌈 Make it safe, efficient and fair for those in need of help

EUROPEAN POLICY AUDIT ON FERTILITY: THE PATIENT PERSPECTIVE

How to continue?

- 🌈 Further research, study and data to understand the needs of infertility patients
- 🌈 Honest dialogue between patients and all stakeholders

TIME

The Test-Tube Baby

Birth Watch in Britain

Evening News LATE SPECIAL

Meet Louise, the world's first test-tube arrival

SUPERBABE

Wide-eyed Louise Brown pictured in hospital 18 hours after she was born. Today she's doing well. See Page Three

The Australian Women's Weekly

EXCLUSIVE Meet the world's first test-tube baby "I am the centre of a very special miracle" says Lesley Brown

THE WEEKLY NEWS FASCINATING BOOK SERIALIZATION BEGINS PARENTS TELL FRANK STORY

WORLD'S FIRST TEST-TUBE BABY

OUR MIRACLE CALLED LOUISE

Powerful human drama behind a great medical achievement

SHOCK UPSET AFTER FIRST OPERATION

I was crying so much John picked me up and carried me to train

EXCLUSIVO! ILLUSTRATO! "PARENTS"

Pour toutes les femmes et pour notamment les hommes attirés, c'est

LE BÉBÉ DU SIÈCLE

Des couples optiques de "Parents" en Angleterre Françoise Couët, Catherine Singer et Benoît Chénou

Les mariages précoces qui servent alors une cause ont été réalisés par les parents de la petite Louise, le premier « bébé-éprouvette ». In un monde qui offre ormai esclusivamente il piacere dei genitori de « Parents ». Non sono disposti a cedere la cocca e il bacio di un bambino di loro proprio a quella infanzia perché quell'è un esultanza d'una parata universale. Il marce lo debut d'una prodigiosa comparsa. A l'abbe di 19 settimane, l'uomo esultanza a multiplier les mystérieux mécanismes de sa propre reproduction.

Daily Mail

First test-tube baby is born and medical history made as a mother's dream comes true

IT'S A GIRL

THE WORLD'S first test-tube baby was born last night - a 5lb. 12oz. girl.

World's greatest weekly for women

WOMAN

EXCLUSIVE THE EXTRA LOVE STORY THE WORLD NEVER KNEW revealed by parents of test-tube baby Louise

HARVEY SMITH & JANE... why they love to hate each other. Frook-around-the-clock 3 in 1 pattern

News

ALL SET FOR BIG LAUNCH

Campaign ready to go

Happy birthday to you!

Louise invites 8,000 to celebrate at Thorpe Park

Daily Mail

And here she is... THE LOVELY LOUISE

CHE RISCHI HA CORSO LOUISE?

parents

En exclusivité mondiale LES SEULES PHOTOS DU BÉBÉ-ÉPROUVETTE

Sondage national "parents: Hög" | Supplément 17 pages LA VIRGINITÉ EN 1978 | RENTRÉE DES CLASSES

stern

Exklusiv: Das Retorten-Baby

Die Geschichte der Tochter Wird der STERN pride?

At 11.47 pm, on July 25th 1978, to every childless couple, hope was born.

THE OBSERVER

A Matter of Life. Starting on Sunday. Only in The Observer.

News

Wow - Look at World's 1st Test Tube Baby Now

10!

Happy birthday to you!

Louise invites 8,000 to celebrate at Thorpe Park

10!

Wow - Look at World's 1st Test Tube Baby Now

OGGI

UN ECCEZIONALE DOCUMENTAZIONE

LA BAMBINA DELLA PROVETTA

- Le fotografie della nascita
- Il giudizio dei medici
- Il memoriale dei genitori

LE FOTO PIÙ BELLE DELL'ANNO LE VACANZE D'AMORE DI CAROLINE E JUNOT

"IVF is not about making babies - It's about creating families."

- Louise Joy Brown -