fertility
About the Starting Families study

Merck Serono, in collaboration with Cardiff University, has conducted the largest-ever international study – Starting Families – among over 10,000 women and men trying to conceive, to gain insight into their decision-making around fertility and fertility treatments.

The study was conducted online at [www.startingfamilies.com](http://www.startingfamilies.com) during 2009-2010 and surveyed couples in: Australia, Brazil, Canada, China, Denmark, France, Germany, India, Italy, Japan, Mexico, New Zealand, Portugal, Russia, Spain, Turkey, UK and USA.

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Foreword

Infertility is a significant problem affecting about 1 in 10 couples worldwide.1 Over 70 million couples struggle to become parents or to conceive another child.1

Being denied the personal fulfilment of having a child can lead to a significant psychological burden and social isolation. From a societal perspective, infertility raises questions of inequalities of access to treatment and it exacerbates declining fertility rates.

Although modern fertility treatments are effective, only a fraction of couples are getting help. It is estimated that only six in ten couples with infertility seek medical advice and just two in ten receive medical care.1

The Starting Families study provides global insights into contemporary fertility decision-making around conceiving a child and seeking medical help in instances where infertility exists. We hope that its findings will enable media, healthcare providers, policy-makers and other stakeholders concerned with fertility, to help more couples become families and to address the challenges they face along the way.

Fereydoun Firouz
Head of the Global Business Unit Fertility and Metabolic Endocrinology
Merck Serono

There is ample evidence for significant change in fertility trends worldwide. Fewer men and women are having children, parenthood is postponed to a later age and family size is shrinking, and few people seek medical advice when they can’t conceive spontaneously.

Starting Families is the landmark study that helps broaden our understanding of the barriers making it difficult for couples to start families in today’s world, whichever country or culture.

The results of the study highlight that inability to discuss fertility issues with close friends and family, and poor knowledge of fertility and treatments, are still major hurdles to seeking medical help around the world.

I hope that this report will help transform the ways we think about infertility and support couples trying for a baby.

Professor Jacky Boivin
Co-leader of the Starting Families study
Cardiff School of Psychology
Cardiff University
Section 1
Fertility – Findings from the international Starting Families study

Fertility – Findings from the international Starting Families study

The Starting Families study uncovers the story behind factors influencing the decision to have a child and seek fertility treatment if challenges should arise. It reveals what people know about their own fertility, how they perceive fertility treatments and what barriers they face to seeking treatment.

Methodology:
The final sample consisted of 10,045 people currently trying to conceive.
The key characteristics of the population that participated in the research were as follows:
- 83% women, 17% men
- 61% of the sample declared that they were treated for infertility problems
- Respondents from Europe represented 54% of the total sample, whereas 27% came from the Americas, 16% from Asia Pacific and 3% from other countries

How to interpret the data:
Please note that the results are not representative of the general population, but are representative of the people that participated in this survey. Therefore, each time that 'people', 'men', 'women' is cited in the text below, one should read it as people, men, women who participated in the survey. Likewise, each time that a country is mentioned, one should read the statement as representative of the participants interviewed from that country, and not necessarily representative of the total population of that country.
1. What makes people ready to conceive?

Most people desire children but not all need them to achieve life satisfaction:

- Need for parenthood (the importance of having children for achieving life satisfaction) is greatest in Russia, France, India and Brazil and lowest in Japan

Men have a weaker desire for children and a lower need for parenthood than women. Contrary to expectations, men perceive more social pressure to have a child and are more willing to comply with these norms than women. An interpretation of this would be that men seek to become fathers to meet social obligations rather than to satisfy a personal need.

Social value attached to parenthood and children, and associated economic benefits, are key factors that provide insight into possible reasons why fertility rates differ across countries, followed by subjective sense of economic security and personal and relational readiness. Influencing factors vary between men and women and across countries.

- Even though men and women value personal and relational readiness the most, they differ on the second most valued motivations. Men are more concerned by physical health and child cost, followed by economic pre-conditions and social status of parenthood, whereas women place economic pre-conditions before physical health and child cost.

- The social status of parenthood is more influential in China and India than it is in other countries. Respondents in these countries are also more willing to comply with partner, family, in-law and community expectations. Interestingly, social status of parenthood seems to be less valued in countries with a higher level of economic development, with the exception of the US, Germany and Japan.

Economic security is given the highest importance in Germany and Denmark and the lowest in Turkey, Russia and Italy.

### Importance of Economic Security

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### Importance of Social Status of Parenthood

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### Importance of Relational and Personal Readiness

The importance of relational and personal readiness is highest in Denmark and the UK and lowest in Japan and China.

Perspective from J. Boivin

Starting families today is a complex affair involving numerous considerations and pre-conditions. Some decisional aspects are (nearly) universal – desire, need for economic stability – others are country specific.

Declining need and value of children and other sources of life satisfaction (especially for women) are important considerations. Decrease in the total fertility rate (TERIA) is cost of success of equality policies & actualisation of people’s economic & aspirational goals.

Policy-makers may face a number of challenges trying to reverse fertility trends:

- Reinventing the value of parenthood for contemporary society. Social status of parenthood and priority of parenting in developmental life course seems to lose ground in wealthier societies. This is compounded by educational and career aspirations. It may be easier to help those already willing but unable to have children to realise their goals (e.g. increase access to fertility treatments) than to convince those with relatively low desire/need to have them.

- Addressing subjective sense of economic security. Economic pre-conditions depend on a subjective level of security and not on a concrete sum of money therefore monetary incentives alone are not likely to succeed in stimulating birth rates. This contention applies to all aspects of pre-conception nesting and sense of ‘being ready’ for parenting.

- Need for contemporary & tailored policies. Heterogeneity in decisional factors means that policies to improve declining fertility rates need to tackle both shared barriers (e.g. European policies on economic pre-conditions) and decisional factors particularly present in some countries (e.g. Italian national policies reinforcing individual desire and societal need for children).
2. What prevents people with infertility from seeking help?

Starting Families found that acknowledgement of a fertility problem, being able to disclose it to partner, family and friends, knowledge about treatment cost and positive attitude towards treatment are among the key factors characterising people who seek medical help.

Interestingly, desire to have children, the need for parenthood for achieving life satisfaction and the opinion of partner, family and friends about starting or continuing treatment are not among deciding factors.

Women are more aware of their fertility problem, are more open to discuss it with significant others and have a more positive attitude towards treatment than men.

Responses from different countries reveal significant differences, providing insight into why people in some countries may be more likely to seek help than in others:

Awareness of a fertility problem and knowledge about treatment cost is the highest among respondents from New Zealand, Denmark and Portugal and the lowest among respondents from India, Russia, Japan and Brazil.

Respondents in Russia and Japan feel least comfortable about disclosing infertility to partner, family and friends.

EASE OF DISCLOSING INFERTILITY TO PARTNER, FAMILY & FRIENDS

Perspective from J. Boivin

This study reveals a number of factors that, together with the level of treatment access, help to explain why many couples do not pursue treatment and why the level of treatment uptake differs from one country to another.

At a minimum, people need to realise their risk for a fertility problem and need to be discussing this problem with their partner and close ones to initiate treatment. The following areas merit further discussion and research:

Lifting taboos. It is understandable that we may experience discomfort discussing infertility or consider (in)fertility a very private topic. Yet for some people openness to discuss fertility issues may be the deciding factor between becoming a parent or not. How can we create an environment where couples looking to conceive can feel at ease discussing their fertility concerns?

Increasing knowledge. Many do not suspect a potential problem when they should already be seeking help, reducing their chances of conceiving over time. More effort is needed to educate couples on when to seek medical advice and on what risk factors affecting fertility should be avoided or may warrant earlier medical investigation.

Providing balanced information about treatment. Positive attitudes towards fertility treatments play a critical role in the decision to seek help. Attitudes are very much informed through passive exposure (media, internet, public campaigns). Few other medical treatments have caused as much ongoing debate or controversy and this may disproportionately affect what people think of these interventions. It is important to ensure that people have access to balanced and factual information about different aspects of fertility treatments on which to base the fertility decisions that will affect the rest of their lives.
3. How much do people really know about fertility?

Starting Families reveals that fertility knowledge is generally low and varies considerably across countries. The UK, Denmark and Australia show the greatest overall knowledge of fertility, while Turkey, Japan and China show the least.

Men are less knowledgeable about fertility than women. The level of male knowledge is the lowest in Turkey and the highest in Denmark, Australia, Portugal and the UK.

Fertility knowledge is poorest when it comes to understanding fertility risk factors and the facts that help people seek timely medical advice:
- Only 44% of people know that a couple is classified as infertile if they fail to conceive after 12 months of trying. The level of knowledge ranges from 70% in New Zealand to 33% in Italy and 20% in Russia.
- Only 42% know that mumps after puberty can affect male fertility, ranging from 9% in Turkey to 57% in France and the UK.
- Only 32% of people are aware that female obesity may reduce fertility. The knowledge ranges from about 20% in Russia and Japan to 73% in New Zealand.
- Only 44% know that sexually transmitted diseases may have a negative impact on fertility. Awareness ranges from 6% in Turkey to about 30% in Germany, Italy and India and 74% in the UK.

Fertility knowledge of men vs. women (% correct answers)

- Half of respondents wrongly believe that women in their 40s have a similar chance of getting pregnant as women in their 30s. The percentage of correct answers ranges from 12% in Turkey to about 50% in the US and Brazil and 78% in New Zealand.
- Only 42% know that mumps after puberty can affect male fertility, ranging from 5% in Turkey to 57% in France and the UK.
- Only 32% of people are aware that female obesity may reduce fertility. The knowledge ranges from about 20% in Russia and Japan to 73% in New Zealand.
- Only 44% know that sexually transmitted diseases may have a negative impact on fertility. Awareness ranges from 6% in Turkey to about 30% in Germany, Italy and India and 74% in the UK.

4. What do people know and think about treatment options?

Most people are aware of where they can get medical advice and know of treatments available. Treatments people are most aware of include lifestyle changes, followed by complex procedures like in vitro fertilisation (IVF) and then medications or injections to restore ovulation. Japan, India, China and Russia stand out as the countries with the lowest awareness across advice and treatment options.

Fertility treatment is successful
Fertility treatment is very safe
Children born of fertility treatment are just as healthy as any other child
Fertility treatment is too expensive
Fertility treatment can cause emotional problems
Seeking medical care is embarrassing
People should adopt instead of seeking treatment
Fertility treatment goes against nature

The majority of respondents agree that fertility treatments are safe and successful and that children born of fertility treatment are just as healthy as any others. People generally do not consider fertility treatments to be ‘against nature’ or something that should be dismissed in favour of adoption. There is a strong feeling that treatment is expensive and can be stressful.

Attitudes towards fertility treatment (1=strongly disagree, 5=strongly agree)
5. Are people getting helpful information about fertility?

People turn to a variety of sources for information about fertility, but not all are equal when it comes to being helpful:

- Fertility specialists and fertility websites are seen as the most helpful sources. Interestingly, people view the information received from general doctors and gynaecologists as ‘helpful’ or even ‘less helpful’ than information from the internet.

- The mass media (newspapers, magazines, radio and television) is not seen as particularly helpful. Perception of the quality of fertility specific information presented in mass media is mixed according to country, but no country rates the quality as good.

- Negative attitudes to treatment are associated with a less favourable perception of the quality of information in the media and of its portrayal of fertility treatment. In contrast positive attitudes to treatment are associated with more favourable perceptions of the quality of information and of how fertility treatments are portrayed.

Helpfulness of information (1=not at all helpful, 5=extremely helpful)
Fertility: The Real Story – Facts and perspectives on fertility

1. Fertility facts & figures

Infertility is a disease. The World Health Organization defines infertility as a disease of the reproductive system defined by the failure to achieve a clinical pregnancy after 12 months or more of regular, unprotected sexual intercourse.²

Over 70 million couples experience fertility problems.¹

Infertility is a couple issue. Male infertility is the primary diagnosis in approximately 25% of cases and contributes to a further 15% to 25% of the remaining cases. 20% of cases remain unexplained.³

Modern fertility treatments are effective. In a recent Danish study 69.4% of treated couples had at least one child within 5 years. Only 6.6% conceived spontaneously outside treatment.⁴

About 8 out of 10 couples seeking medical care do not start, or persevere with the treatment journey.⁵-¹⁰

Emotional distress is the key reason mentioned by couples who discontinue treatment.¹¹

2. Fertility pathway

Trying
- Have unprotected sex approximately every 2-3 days
- Try to have sex during the female partner’s fertile phase, which is at the time of or just before ovulation (~14 days from the length of the female partner’s average menstrual cycle)
- Live a healthy, balanced lifestyle
- Relax... 80% of couples get pregnant within the first 12-18 months

Seeking medical help
- Typically, a doctor or gynaecologist will provide information about fertility and may carry out preliminary tests
- Couples may be referred to a specially trained fertility expert for comprehensive testing and treatment

Testing & diagnosis
- Tests are designed to assess the following four key elements:
  - The right balance of hormones to allow egg and sperm development and support
  - The female’s ovarian reserve and whether ovulation is taking place
  - The quantity and quality of male sperm
  - The ability of both the male and female reproductive mechanisms to allow fertilisation to take place
- Tests may need to be repeated, requiring two or three visits to the clinic

Day clinic
- In some cases simple surgery is all that is needed to allow a couple to conceive naturally. Several modern techniques for both men and woman (e.g. laparoscopy and hysteroscopy) can be completed in a simple day visit to a clinic

Oral medication
- If the female partner is not ovulating, she may be advised to take a drug such as clomiphene citrate, the most commonly used drug to stimulate ovulation

Hormone treatment
- Hormone injections may be required if one or both partners has a problem producing the necessary amount of hormones to produce enough healthy sperm and eggs
- Injections can normally be administered by couples at home
- Regular check-ups at a clinic will be needed to ensure that the hormones are effective
- Hormone treatment may be combined with other fertility treatments, depending on a couple’s diagnosis

Assisted reproductive techniques (ART)
- If other treatments fail and the problem is with a couple’s ability to achieve fertilisation a range of modern techniques may help:
  - In Vitro Fertilisation (IVF). Hormonal injections are given to a woman to stimulate the production and release of multiple eggs. Once the eggs have matured, a fertility specialist retrieves them from the woman’s ovaries. Eggs and sperm are united in a laboratory dish and two-three days later, one or more embryos are transferred into the woman’s uterus
  - Intracytoplasmic Sperm Injection (ICSI) is a lab procedure where a single sperm is injected into the egg cell to help fertilisation. ICSI is often performed in conjunction with IVF

Adapted from The Assisted Conception Taskforce (ACT) booklet: Trying for a baby? Your step-by-step guide to assisted conception. www.assistedconception.net
3. History of fertility treatments

1924–1949 Irradiation of the ovaries and pituitary (the gland producing follicle stimulating hormone – FSH – and luteinizing hormone – LH) is first used to stimulate ovarian function. The treatment is stopped in 1965

1941 Pregnant mare serum gonadotrophin (PMSG) and human chorionic gonadotrophin (hCG) is used to treat infertile women

1949-1950 First human menopausal gonadotrophin (hMG) is extracted from post-menopausal women’s urine and registered by Serono as Pergonal

1962 First baby girl was born after treatment with Pergonal

1970s FSH is known to be the primary hormone causing follicular development

1978 Louise Brown, first IVF baby, is born

1980s Serono develops Metrodin, the first ‘biologically pure’ FSH still extracted from urine

1993 Serono registers Metrodin HP, highly purified FSH preparation

1995 Serono registers Gonal-f, the first human FSH produced with the recombinant DNA technology that no longer requires extracting FSH from human urine

2001 Serono has a full recombinant human gonadotrophin portfolio including FSH, LH and hCG

4. Fertility in the 21st century

Fertility rates are declining globally. In Europe fertility rates have fallen to 1.41 children per woman, well below the 2.1 children per woman required to support the size of the population. This may bring new socio-economic challenges around supporting aging populations and sustaining economic growth.

Global fertility rates

Infertility is common. It is estimated that 9.6% of couples face infertility. The trend of delaying parenthood may contribute to the increasing number of couples struggling to conceive.

The majority of couples with infertility remain untreated. Although effective treatments are available, only 56% of infertile couples seek 22% receive medical care against infertility. Persisting social and personal barriers, low fertility awareness and limited treatment access and reimbursement, are among key factors contributing to this gap.

Access to advanced fertility treatments varies significantly across countries. It is estimated that in vitro fertilisation (IVF) and intracytoplasmic sperm injection (ICSI) treatments are available in 45 out of 191 World Health Organization (WHO) member states. The number of treatment cycles performed per million population ranges from 2 in Guatemala to 3,688 in Israel.

Advanced fertility treatments are not reimbursed in the majority of countries. Full or partial coverage of assisted reproductive technology (ART) treatments is available only in Western Europe, Australia, Israel, Korea and some US states. When available, access to ART reimbursement is often restricted by age of woman, number of children and number of treatment attempts.

5. Fertility myths

IVF can fix anything. Success rates for IVF vary and while they can be as high as 75%, the higher rates of success are usually achieved after multiple attempts. And invariably, younger women fare better, although egg donation can improve the chances of older women conceiving through IVF.

The research assessing the degree to which IVF can help older women increase their chances of conceiving concludes that if a woman postpones an attempt to become pregnant by 5 years (from age 30 to 35), her chances of conceiving will be reduced by 9% and ART will only make up for 4% of the reduction. A woman aged 35 to 40 years will have a 25% reduction in her chances of conceiving and ART will make up for only 7% of that.11

This sends a clear message to women 35 years or over who have not conceived after six months of trying – do not delay seeking help because even the most advanced treatments cannot make up all births lost by the natural decline of fertility with age.

Fertility treatments mean multiple births. Using drugs to stimulate the ovaries to produce multiple eggs can result in multiple embryos and multiple pregnancies. And transferring more than one embryo per IVF treatment cycle may result in more than one baby being born.

This may sound like an attractive and cost-effective strategy for couples desperate to have a baby but who cannot afford multiple IVF attempts. It may also be appealing to couples who face time pressures on becoming a parent because of their age. However, multiple pregnancies pose potentially serious health consequences for both mothers and children. The ESHRE Task Force on Ethics and Law recommended in 2003 that the aim of fertility treatment should be to produce a singleton pregnancy only. They also recommended that women under 38, who have normal ovarian function and a good fertilisation rate, should have only one or two embryos transferred.16

Policies that restrict the number of embryos transferred are already effectively reducing multiple birth rates. Globally, since 2000, the percentage of single embryo transfers has increased by almost 2%, with the highest proportion of such transfers being seen in Finland and Sweden (38.5% and 30.5% respectively). As a result, the percentage of triplet births is very low, at just 0.2%, in both countries.17

It’s encouraging to note too that although fewer embryos are being transferred each time, this has not resulted in a drop in the number of babies born overall. In Sweden, despite a successive reduction in the number of embryos transferred, delivery rates per treatment cycle have been maintained at around 26%.15
6. The real costs of infertility

Advanced fertility treatments are not reimbursed in the majority of countries. Reimbursement of fertility treatments is rarely a priority on the agenda of policymakers and payers. Often the discussion focuses on the cost-effectiveness of investing limited public resources into infertility treatments compared to other healthcare priorities. While specific circumstances may differ by country it is important that the decision-makers and public consider a broader perspective.

Infertility is a disease. The World Health Organization (WHO) defines infertility as a ‘disease of the reproductive system’. Infertility prevents people from realizing an important life goal – the possibility to parent a genetically related child or a child created within the current relationship.18

Infertility can create inequality. The ability to have children should not depend on personal income. For many couples the cost of advanced treatments is high. The cost of a standard IVF cycle ranges from 12% of an individual’s annual income in Japan to 50% in the US.19 In developing countries like China and India, the cost of IVF can be 50% higher than the gross national income per capita.20 At the same time, the cost of providing treatment is relatively low for a society. In Scandinavian countries, where the levels of ART utilization and reimbursement are among the highest in the world, it accounts for less than 0.2% of the total healthcare expenditure.19

Lack of reimbursement goes hand in hand with health risks and costs of multiple births. When paying for treatment themselves couples have a strong financial incentive to achieve pregnancy in the minimum number of treatment cycles. Attempts to increase pregnancy chances by transferring more embryos, result in multiple births that create important life goals – the possibility to parent a genetically related child or a child created within the current relationship.18

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ART can support total fertility rates. Many countries face significant long-term socio-economic challenges due to declining fertility rates and aging populations. A study comparing the use of ART in Denmark and in the UK concluded that increasing IVF uptake in the UK to Danish levels could result in the UK total fertility rate increasing from 1.64 to 1.68 children per woman. Further, it concluded that the direct costs associated with adopting ART as a population policy are comparable to those of existing policies commonly used by governments to influence fertility.22

7. An IVF success story

“...”

43 year old Helen and her husband Steven (51) have two children – Nathan and Scarlet – thanks to IVF.

Helen tells the story of their journey to parenthood.

Denmark – the case study

Denmark has one of the highest uptakes of infertility treatments – 4.2% of babies in 2002 were born due to assisted reproductive technologies, compared to just 1.4% in the UK and 1.2% in the US. In Denmark, IVF is widely accepted, publicly subsidised* and waiting times for treatment are short. This has helped keep Denmark’s birth rate high at 1.9 children per woman, close to the 2.1 babies per woman needed to maintain population levels.13

* The provision of reimbursement for ART in Denmark is currently under legislative review

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Looking back, 100% of couples who had a baby after treatment, and 91% of those who didn’t, say they are happy they underwent treatment cycles to succeed. Most stressful experiences have to do with the disappointments of treatment failure or waiting for treatment results. The psychological burden is the key reason for this. Up to 54% of couples drop out of IVF, without achieving pregnancy, before they complete three cycles of treatment. The level of distress in infertility patients tends to increase as treatment intensifies and as the duration of treatment continues. By the time couples get to try IVF, they will have gone through many months of trying to conceive and failures of less complex treatments, so their distress is high.

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References

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International placement partners
BabyCentre
www.babycentre.co.uk
ClearBlue
www.clearblue.com
ICSI, International Consute Support for Infertility
www.icsi.org
Ipsos Sante
www.ipos.fr
Australia
ACCESS Australia Infertility Network
www.access.org.au
PDSA, Polycystic Ovarian Syndrome Association of Australia
www.possa.org.au
The Bub Hub
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Herlev Hospital
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Landstinget For Utvilsigt Barni
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Italy
Saisinfertilita
www.saisinfertilita.net
Mexico
AMI, La Asociación Mexicana de Infertilidad
www.ami-az.com
New Zealand
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www.fertilityassociates.co.nz
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