

STATES OF JERSEY



IN VITRO FERTILISATION (IVF) FUNDING

**Lodged au Greffe on 9th April 2024
by Deputy L.K.F. Stephenson of St. Mary, St. Ouen and St. Peter
Earliest date for debate: 30th April 2024**

STATES GREFFE

PROPOSITION

THE STATES are asked to decide whether they are of opinion –

to request the Council of Ministers to commit to improving funding for In Vitro Fertilisation (IVF) treatment, removing the current means-tested model, and ensuring any new funding model reflects National Institute for Health and Care Excellence (NICE) clinical guidance, and to ensure that such funding is included within the Proposed Government Plan 2025-28.

DEPUTY L.K.F. STEPHENSON OF ST. MARY, ST. OUEN AND ST.
PETER

REPORT

Declaration:

I am a founding governor of the local fertility support charity Tiny Seeds and have lived experience of infertility and IVF. I have no financial interest, however, and have taken advice on my charity position in relation to this matter and am content that this should not be barrier to me bringing such a proposition, particularly as working towards an improved funding model for IVF was a manifesto commitment. Tiny Seeds is the only charity of its kind in the Island and therefore it has not been possible to avoid using its local data in this report, given its valuable nature to the issue under discussion and often a lack of such data from government.

In addition, it should be noted that I also have no personal financial interest in this proposition as NICE guidance criteria would exclude me from qualifying from funding.

Report

Infertility is a disease, as defined by the World Health Organisation.¹ It affects around 1 in 6 people of reproductive age at some point in their lifetime and can impact on mental as well as physical health, on individuals and families.

Since the birth of the first child following In Vitro Fertilisation in 1978, millions of babies have been born around the world thanks to the procedure. Many others have resulted from lower-level fertility treatments, such as medicines, surgical procedures and intrauterine insemination.

The right to start a family is enshrined in local and international human rights law. The Human Rights (Jersey) Law 2000, which is modelled closely on the UK's Human Rights Act 1998, states: "Men and women of marriageable age have the right to marry and to found a family, according to the national laws governing the exercise of this right."² Providing fair and equitable access to fertility treatment should be considered in this context.

In Jersey, access to low level fertility treatments is, in the main, good and many are funded through the health service. Jersey's Assisted Reproduction Unit sees an estimated 180 new referrals per year, and there is currently no waiting list. The service is not yet universal for all, however, and requires improvement.

But for those requiring IVF treatment – last year 51 couples had IVF cycles facilitated via the ARU – funding remains a major barrier for all. The Cost-of-Living crisis is making it worse.

Evidence collected by the local fertility support charity Tiny Seeds as part of its Cost of Living and IVF Impact Survey 2023³ shows that some Islanders requiring IVF have no other choice but to put themselves into debt, others are having to choose between trying to have a family and buying a home, and some have even left or are considering leaving the Island, either for a cheaper way of life which will allow them to fund their treatment

¹ <https://www.who.int/news-room/fact-sheets/detail/infertility>

² <https://www.jerseylaw.je/laws/current/Pages/15.350.aspx>

³ <https://tinyseeds.je/images/icons/The-Cost-of-Living-and-IVF-Tiny-Seeds-Impact-Survey-Findings.pdf>

or because other jurisdictions will offer them better access to treatment, or a combination of both. Others are not able to access treatment at all.

Following the publication of the Jersey Health Profile for 2022, which showed that the average age of new mothers in Jersey was 33 compared to a UK average of 30, Jersey's consultant who leads on assisted reproduction, Dr Enda McVeigh, said publicly that it was his view that the cost of living was forcing some women to pursue having children later in life. In turn, he added this can lead to a drop in fertility rates as fertility declines with age.⁴

His predecessor, the respected local consultant gynaecologist Neil MacLachlan, also spoke out on the same subject in 2022 and warned it was his view that Jersey's high cost of living meant families were delaying having children, risking higher levels of infertility and potentially more complicated pregnancies. As well as the obvious personal tolls of more complicated pregnancies, they can also cost more in healthcare. He said: "We have to ask ourselves, why are women choosing to become mothers at an older age in Jersey? There could be several factors, but it is my belief that most of these relate to affordability and employment. The steep cost of living in the Island means Jersey has high numbers of households that are reliant on double incomes, childcare costs are high, there is a shortage of affordable accommodation. Higher divorce rates in Jersey, compared to the UK, are also a factor, with more relationships starting later in life."⁵

Mr MacLachlan said that the solution was for parenthood to be framed as a "societal concern that workplaces and Government have a duty to address".

Jersey's fertility rate (the total number of births per 1,000 women of child-bearing age 15-44) for 2020-2022 was among the lowest in the world at 1.3, and was the lowest for the island in 27 years.⁶

A fertility rate of 2.1 is required to maintain a stable population.

Jersey has unique characteristics, including a high female labour participation rate, which are all contributing to these fertility trends.

Consider also the long-term demographic challenges facing our Island – particularly the ageing population – and it is even harder to deny this is a societal concern that we have a duty to address.

I was pleased that the Chief Minister, Deputy Lyndon Farnham, indicated his own acknowledgment to this end in answer to oral questions during the States sitting on 27 February 2024:

13.5.8 Deputy L.K.F. Stephenson:

"I am pleased that the Chief Minister mentioned I.V.F. treatment in there. He almost read my mind for my supplementary question. Does the Chief Minister agree with me that addressing the outdated and inadequate means-tested model for funding high-level fertility treatment that we currently have in Jersey, which

⁴ <https://www.itv.com/news/channel/2023-02-27/rising-cost-of-living-means-more-women-having-children-later>

⁵ <https://www.bailiwickexpress.com/jsy/news/jersey-families-delaying-children-due-cost-living/>

⁶ <https://www.gov.je/StatisticsPerformance/Health/pages/birthsandfertility.aspx#anchor-3>

is currently set a level so low that no one has ever qualified for it, would be a very positive place to start to support those wanting to start or grow their families?

*Deputy L.J. Farnham:
Absolutely, yes, I do.”*

The Health Department has been working on a piece of policy research and development focused on assisted reproduction and its associated costs for around a year. The previous Health Minister, who had included that work in her Ministerial Plan, had committed to bring forward proposals for improvements to the funding as part of the next Government Plan.

This proposition asks States Members to ensure that work does not go to waste and is used to inform an improved offer for Islanders who need the help of IVF to start or grow their families.

How is IVF currently funded in Jersey?

It should be noted that infertility is not the only reason someone may require IVF, it is also used by same-sex couples and single people hoping to start or grow their families. IVF cannot currently be carried out in Jersey and patients must travel to private clinics outside of the Island for treatment, which adds to the cost. ARU acts as a satellite clinic, providing monitoring on Island until such a time that the patient is ready for treatment at a full fertility clinic.

Currently, the government covers the medication costs for up to 3 cycles of IVF for couples aged under 42 (circa £1,000 per cycle). Means-tested funding is then available to cover the remaining full cost of treatment for couples with a combined income of up to £40,795. That eligibility criteria is so low that there is no evidence that anyone has ever qualified for it. The answer to written question 75/2024 confirms that there were no state-funded IVF cycles in 2023⁷, reflecting the trend from previous years.

To put it into perspective, according to the most recent Average Earnings Index for Jersey⁸, the mean average annual salary for someone working full-time was £47,840. A couple both working full-time in hotels, restaurants and bars (the lowest weekly earnings category cited in the report) would have a combined household income of £61,360 – way below the eligibility criteria.

Two people working full-time (based on a 35-hour working week) for the Jersey Living Wage would have a combined income of £48,812. And a couple both working full-time for the minimum wage would also be ineligible, with a household income of £42,386. A total of 32% of respondents to the Tiny Seeds Cost of Living Survey said they had or would have to delay starting treatment because of finances, while 5% said they were unable to access treatment at all due to the cost.

The Health Department has confirmed that IVF is the only healthcare treatment it provides which is subject to means testing. Jersey is also the only place in Europe understood to mean-test for IVF support.

⁷ <https://statesassembly.gov.je/assemblyquestions/2024/wq.75-2024.pdf>

⁸ <https://www.gov.je/SiteCollectionDocuments/Government%20and%20administration/R%20Average%20Earnings%20June%202023%2020230825%20SJ.pdf>

Current practice in Jersey dictates that same sex couples are treated the same as heterosexual couples in accessing assisted reproduction services once an infertility diagnosis has been made. Therefore, ARU currently provides the same funding to same sex couples as it does to heterosexual couples and this proposition assumes that practice will continue under any new funding model.

ARU supports around ten female same sex couples per year.

Same sex male couples wishing to have a child require surrogacy, arrangements for which are not currently available or funded through ARU. Although mindful of the need to improve equality of access and sympathetic to their situation, this proposition does not seek to change those arrangements as surrogacy is not currently covered in any form - for heterosexual or same-sex couples - by NICE clinical guidance.

In addition, ARU currently sees around 5 or 6 “single mothers by choice” – women who seek IVF treatment in the hope of having a child on their own using donor sperm. They are not currently funded and, again, although sympathetic to their situation, this proposition does not seek to change that arrangement.

I would, however, strongly encourage ministers to consider these two groups in any future policy development, regardless of whether this proposition is approved or not.

What does IVF cost?

The cost of a full cycle of IVF treatment varies according to the clinic and specific treatment protocols. However, data for average costs has been provided by the Health Department. It estimates that on average a cycle of IVF costs £4,800, or £6,600 with ICSI (Intracytoplasmic sperm injection – where a single sperm is injected into an egg). According to the department, around half of all cycles will involve ICSI.

In addition, the department estimates that due to the need to travel off-island for treatment couples spend an average of £900 on travel and accommodation (5 nights) per cycle. Couples who responded to the Tiny Seeds Survey put this figure at more like £1,000 to £2,000 per cycle. It should be noted that due to the nature of treatment travel is usually booked at the last minute, which can increase the cost.

Frozen embryo transfers (where embryos created in an earlier part of the cycle are thawed and transferred) currently cost £2,050 at the Lister Fertility Clinic and £2,595 at the Bristol Centre for Reproductive Medicine (the 2 most frequently used clinics by Jersey patients).

The 56 patients who responded to the Tiny Seeds Cost of Living Survey had spent an average of £17,689, including travel and accommodation, on IVF to date, with 87% of them saying that they would require further treatment.

The NICE guidelines

The National Institute for Health and Care Excellence has long-established clinical guidance for funding access to IVF treatment.

The full details can be found can be found at appendix 2, but broadly speaking NICE recommends funding:

- 3 full cycles of IVF for women aged under 40, subject to meeting a number of criteria
- 1 full cycle of IVF for women aged 40-42, subject to meeting certain criteria

A full cycle is defined by NICE as follows: “A full cycle of IVF is one in which 1 or 2 embryos produced from eggs collected after ovarian stimulation are replaced into the womb as fresh embryos (where possible), with any remaining good-quality embryos frozen for use later. When these frozen embryos are used later, this is still considered to be part of the same cycle.”

Jersey looks to NICE clinical guidance for good practice across many services and IVF should be no different. The guidelines are also based on chances of success, and recognise that after the age of 42 the chances of IVF being a success are reduced.

How does Jersey compare?

The UK government states that it expects regional integrated care boards to commission fertility services in line with NICE clinical guidance to ensure ‘equal access’ to treatment across England. However, in reality the implementation of the guidance varies, even to the point that north-west London provides for 3 funded cycles compared to north-east London which provides for 1. Different areas also use different qualifying criteria.⁹

Scotland, by contrast, follows the NICE guidance in providing 3 cycles for those aged up to 40, and 1 cycle for those aged 40-42. Access criteria is standard across the country. In Wales, the Welsh Health Specialised Services Committee sets criteria and provides for 2 full cycles for women up to the age of 40 and 1 for those aged 40-42. Again, access is subject to various criteria which is standard across the country.

In February Northern Ireland announced it was improving its funded IVF offer to 1 full cycle for those who qualify.

Guernsey currently does not provide any financial help towards the cost of IVF but does provide some support with travel and medication costs.

In the Isle of Man, patients under the age of 40 are offered 1 fully funded cycle subject to various criteria.

Portugal funds the first 3 cycles, while in November the Polish Parliament voted to reinstate government funding for IVF. The changes are due to come into effect in 2024 with politicians there promising the funding will “guarantee a wide access to IVF procedures”.¹⁰

Fertility Europe, working in partnership with the European Parliamentary Forum for Sexual and Reproductive rights, has developed the European Atlas of Fertility Treatment Policies. The full atlas can be viewed at Appendix 4.

⁹ <https://www.gov.uk/government/publications/nhs-funded-ivf-in-england/nhs-funded-in-vitro-fertilisation-ivf-in-england>

¹⁰ <https://www.politico.eu/article/poland-parliament-moves-restore-in-vitro-ivf-funding/>

The current data sets out a comparison of jurisdictions as of 2021, and ranks countries according to a set of criteria which considers four main areas: regulations, treatments, funding and education.

Belgium (with a score of 86), Israel (86), the Netherlands (86) and France (84) all top the Atlas and are rated “excellent”, with the UK in 10th position and categorised as “very good” with a score of 75.

Although Jersey does not feature in the 2021 Atlas, Tiny Seeds worked with Fertility Europe to measure Jersey against the same criteria. The Island scored a total of 37, meaning it would be categorised as “very poor” alongside countries such as Belarus (31), Bosnia & Herzegovina

(37, 42), Czech (49), Georgia (34), Switzerland (33) and Turkey (33).

Although an “unofficial” rating, this information was shared with the Health Department and policy researchers.

Funding is just part of the criteria for the Atlas and the poor rating for Jersey exposes other weaknesses in our local system, including our lack of a donor register and Assisted Reproduction Technology law.

The psychological impact

A 2022 survey by Fertility Network UK lays bare the mental impact of fertility treatment, with 4 out of 10 respondents saying they had experienced suicidal feelings, 30% reported suicidal feelings sometimes or occasionally, while 10% experienced suicidal feelings often or all the time.

Approaching half (47%) of respondents experienced feelings of depression often or all the time, while the vast majority (83%) felt sad, frustrated and worried often or all the time.¹¹

In its own survey of Jersey residents, Tiny Seeds found that 87% of those who responded thought about their fertility struggles either daily or all of the time, 69% said this made them feel depressed, 88% anxious, 6% suicidal, 81% lonely and 75% isolated.

The financial burden of fertility treatment adds to the stress and anxiety. The Tiny Seeds Cost of Living survey found that 96% of respondents said their mental health had been negatively impacted by the cost of living, specifically in relation to their ability to pay for treatment (46% a great deal, 29% a moderate amount, 21% a little).

Delaying treatment to save up to pay for it can also impact on its chances of succeeding as fertility declines with age, the reduction happening even faster after the age of 35.¹² For some, their body clock literally is ticking.

Fertility treatment is physically and mentally demanding, and can dominate a person or couple’s life. There also remains a certain taboo around talking about infertility, which can further add to the challenges. Those going through it often talk about feeling lonely, inadequate, like their lives are on hold and report their self esteem suffering. Work can be impacted, and relationships strained. Some people will use all of their leave from work for treatment, but are then left with no time to take a break or holiday to unwind.

¹¹ <https://fertilitynetworkuk.org/the-far-reaching-trauma-of-infertility-fertility-network-uk-survey/>

¹² <https://www.britishfertilitysociety.org.uk/fei/at-what-age-does-fertility-begin-to-decrease/>

Infertility does not discriminate, yet Jersey's policy towards funding treatment continues to do so.

Long overdue

In January 2021, Jersey's medical director Patrick Armstrong acknowledged that the current funding model needed attention, and said publicly the aspiration was to be able to provide a system similar to Scotland, where the government funds up to 3 cycles of IVF for qualifying couples regardless of their income as long as the woman is below the age of 40. For those aged 40 to 42 1 cycle is funded. He said that work on the funding model would start that year.¹³

More than three years on, work on the funding model has not yet started. Encouragingly, however, the previous Health Minister, Deputy Karen Wilson, commissioned a review of assisted reproduction services in order to collect the data needed to make informed decisions around future policy and funding. The journey was finally starting!

There appears to be wide agreement among policy makers and politicians that improvements need to be made and the current system is outdated. It is time to act on those words and the promises that have been made to patients and potential future patients that change is coming.

Furthermore, if ministers are to deliver on their commitment to develop a truly sustainable funding model for healthcare, then that model should be based on service offerings which are modern, fair and accessible.

The economic case

The Government of Jersey's Common Population Policy Annual Report for 2023¹⁴ sets out in stark detail the demographic challenges facing the Island in the future. It warns: "Using the 2021 Census figures, it is possible to make estimates of future population figures based on different theoretical migration levels. In particular these estimates can demonstrate the future likely split between working age (16-64) and non-working age (children and people aged 65+). Under all migration levels, the dependency ratio (the ratio of working age people to non-working age people) gets worse. An increasing ageing population is also likely to put increased pressure on public services such as health and social care."

The report goes on to explain that the Island's total fertility rate – the average number of children born to a woman in her lifetime – has declined over the last decade and as of 2023 stood at 1.32. That trend is reflected in the UK, but Jersey's total rate is lower. And the report sets out the potential challenges of using immigration as the only source of population growth in order to sustain – not even improve – the Island's current economic situation.

¹³ <https://jerseyeveningpost.com/news/2021/01/28/ivf-to-become-more-accessible/#:~:text=Patrick%20Armstrong%2C%20the%20Island%27s%20medical,42%20one%20cycle%20is%20funded.>

¹⁴ <https://www.gov.je/sitecollectiondocuments/government%20and%20administration/common%20population%20policy%20annual%20report%202023.pdf>

The Future Economy Programme is one part of the proposed solution, but working to maintain our own stable population should also be a part of it.

Enabling those who want to have children (future taxpayers) but are impacted by infertility fair and equal access to the healthcare they need to pursue that aim is a logical place to start.

Improving our offer also reduces the chances of today's working age population seeking a life away from Jersey because they cannot afford to live here and pay for fertility treatment. Anecdotal personal experience shows that this has been a very real choice for some couples, including those working in areas with recruitment challenges such as teaching and healthcare.

In 2016 22 babies were born following IVF, and the year after 16. In 2019 it was estimated that 5.2% of the Island's 880 births followed treatment with ARU. Unfortunately – and disappointingly – no statistics have been kept by Health since that point and the department is unable to confirm how many babies have been born following IVF each year in Jersey, however an estimate of 40 has been made.

In the US around 2% of all births are as a result of IVF, and in Australia that figure is 1 in 18.

The authors of “Declining global fertility rates and the implications for family planning and family building: an IFFS consensus document based on a narrative review of the literature” published in January set out the economic case very simply as a “positive return on public investment”.¹⁵

Fertility care is often not affordable for individuals who have to pay out of pocket for such treatments (Dyer, 2002; Ombelet et al., 2008; Chambers et al., 2013; Bahamondes and Makuch, 2014; Koniaries et al., 2022). In contrast, fertility care is very affordable from a societal perspective (Chambers et al., 2009; Connolly et al., 2010; Vélez et al., 2014). Indeed, fertility care is cost-effective and represents a positive return on public investment through the future economic value of babies resulting from fertility treatments (ESHRE Capri Workshop Group, 2015).

“Identifying the optimal economic framework to assess the cost and benefits of fertility care remains challenging because infertility and its treatment are unique in the health care system because its goal is the creation of a new life (Martins and Connolly, 2022). Compelling economic reasons to support increased access to fertility care in most countries include the relatively low societal cost to obtain a live birth, future economic productivity of the resulting individuals, and the high net present value of future tax payments from those individuals” (Connolly et al., 2008; Martins and Connolly, 2022).

The authors also conclude that ultimately providing access to fertility treatment is a human rights matter:

“Article 16.1 of the UN Declaration of Human Rights states that ‘men and women of full age, without any limitation due to race, nationality or religion, have the right to marry and to found a family’: United Nations Charter Article 16 (United Nations, <https://www.ohchr.org/en/human-rights/universal-declaration/translations/english>).

¹⁵ <https://academic.oup.com/humupd/article/30/2/153/7513427#442199462>

The human right of persons to access infertility treatment is consistent with the 1948 UN Declaration of Human Rights and the ICPD plan of action Cairo 1994 (United Nations, <http://www.ohchr.org>; International Conference on Population and Development, https://partners-popdev.org/icpd/ICPD_POA_summary.pdf). Therefore, addressing infertility is fundamental to realizing the right of individuals and couples to found a family (Zegers-Hochschild et al., 2013; Mburu et al., 2023). Infertility treatments must not be limited to the affluent. Although both male and female factors can be the cause of infertility, women bear the most severe consequences and burdens even if they are not the cause of infertility (Starrs et al., 2018; Vollset et al., 2020).”

Financial and staffing implications

Estimating potential demand, and therefore cost, of any new scheme is particularly difficult given the many data gaps which exist within this area of the Health Department. It is also a complex and delicate policy area which requires careful thought and consideration, including how any new policy will interact with those which, for example, provide fertility preservation for cancer patients (which is currently funded).

This proposition therefore calls on ministers to make use of the research carried out by policy officials to inform the proposals they would then bring forward to the Assembly for approval as part of the next Government Plan process, but to do so with an aim of removing the means-testing criteria and implementing NICE clinical guidance.

Members, then, are not being asked in this proposition to agree to a ‘blank cheque’, but to ask ministers to return with the detail for future approval.

That said, some estimates can be made. Between 2008 and 2017, ARU acted as a satellite clinic for 1,291 cycles of IVF – an average of around 129 per year.¹⁶

Last year 68 cycles of IVF were facilitated via the ARU, for 51 unique couples.¹⁷ To fund all of those cycles at the average costs cited in this report, with half at the higher ICSI rate, would cost a total of £387,600. Demand could increase with improved funding, but that would be balanced by the access criteria which would mean not all of those patients would qualify for funding, certainly not all at the same time. Access criteria, which would be set by the department and informed by NICE guidance, can include considerations such as, but not be limited to, BMI, smoking status and existing other children.

Using the ten-year average demand up to 2017, the annual cost of funding all cycles would be £755,300. Again, it is not realistic to consider that all cycles would qualify for funding.

The annual budget for ARU – which also provides many lower-level fertility treatments and investigations on island – last year was £563,613, with private patient income of £8,980. There is not currently a waiting list for appointments at ARU.

Children’s Rights Impact Assessment

¹⁶ <https://www.gov.je/government/freedomofinformation/pages/foi.aspx?ReportID=2217>

¹⁷ <https://statesassembly.gov.je/assemblyquestions/2024/wq.75-2024.pdf>

A Children's Rights Impact Assessment (CRIA) has been prepared in relation to this proposition and is available to read on the States Assembly website.

Appendices

Appendix 1

These Jersey children and families would not be here without the help of fertility treatment. Images courtesy of Tiny Seeds and Sophie Darwin Photography



Appendix 2 – NICE Clinical Guidelines for IVF

[National Institute for Health and Care Excellence Fertility problems: assessment and treatment. Clinical Guidelines](#)

Appendix 3 – What is IVF?

[Fertility Network UK - In Vitro Fertilisation & Intracytoplasmic Sperm Injection](#)

Appendix 4 – Fertility Treatment Policies in Europe

[Fertility Europe - European Atlas of Fertility Treatment Policies](#)

Appendix 5 – Tiny Seeds Cost of Living Survey

[Tiny Seeds: The Cost of Living and IVF – Impact Survey 2023](#)