

Questions for Tiny Seeds Jersey in relation to the proposed additional revenue funding of IVF infertility treatment

1. To what extent do you consider the proposed allocation of £620,000 for IVF treatment in 2025 sufficient to meet the needs of islanders struggling with infertility?

Without knowing further details, for example, whether medication costs will be included in this allocation, or what the cost of a cycle of IVF will be to the Government of Jersey, it is hard to provide an answer to this. Without full statistics for how many cycles of IVF are undertaken in the island per year it is difficult to make a judgement.

What we do know through our IVF travel bursary scheme - which is available to all who need to travel away from the island for IVF, including same-sex couples, single women pursuing parenthood and those who already have children - is that we received 70 applications over the course of a year from the start of August 2023 to the end of July 2024. We allow for one application per individual or couple per calendar year, which means there are some people who have applied up to 2 times included in those numbers. We also accept applications from patients of the Women's Health Hub as well as the Assisted Reproduction Unit. Note that other than the exception noted above, these numbers are not representative of how many rounds of IVF (including Frozen Embryo Transfers (FETs)) take place within a 12 month period.

39 of our travel bursary applicants were undergoing fresh cycles of IVF, with 31 undergoing FETs. Taking into account the lower cost of an FET, this suggests that the £620,000 allocation would likely be sufficient to cover the costs of the full 70 cycles of IVF/FETs that we know about.

Please note that while this budget appears at face value to be sufficient to cover those cycles, without further breakdown of costs and predictions of the true number of cycles undertaken within a year, we cannot make any judgement on whether the £620,000 allocated budget is a sufficient amount.

2. Based on your experience, how many islanders could realistically benefit from this amount of funding?

As outlined above, without further information on the cost of an IVF cycle procured by the Government of Jersey, it is difficult to quantify or be exact. However, a basic fresh cycle of IVF costs in the region of £5,000 upwards including medication, £6,500 when ICSI is required (this is where they inject sperm directly into the egg and is necessary in roughly half of all fresh IVF cycles). An FET is in the region of £3,000. With these figures taken into account, the £620,000 budget could potentially fund around 124 basic fresh cycles of IVF in a calendar year or 95 cycles if they all required ICSI.

Without knowing in detail what is included within a funded cycle there could be significant unaccounted for expenses such as Pre-Implantation Genetic Testing etc on top of a basic cycle and these figures also do not take into account the proposed embryo storage fees for up to 1 year.

Our recent IVF eligibility survey found that out of 80 respondents, only 29 of those believed they would be eligible to receive funding based on the proposed criteria currently outlined by the Government.

3. What are your thoughts on whether the funding allocation will provide equitable access to IVF treatment for all those in need in Jersey?

While it is positive that a budget has been allocated for funded IVF, strict access criteria will see people miss out on funding and therefore it cannot be viewed as equitable.

Proposed restrictions including limited to no-access for those who have previously self-funded treatment, as well as on those who already have a child or children, means that a large proportion of those currently needing IVF in the

island will not qualify. As previously mentioned, the results of our recent IVF Eligibility Survey found that 63% of our 80 respondents believed that they would not qualify to receive the proposed funding. The full results of that survey are attached for you and include the reaction of the individuals who need treatment, to the proposed criteria.

4. Are there any particular groups or individuals who might still struggle to access treatment despite this funding?

Due to the proposed access criteria there are a number of groups who will struggle or be unable to access treatment at all including;

- Single people
- Those where one or both partners already has a child or children
- Those with a BMI which falls outside of the criteria
- Those who have previously self-funded treatment - irrespective of whether they have been successful or not
- Those aged under 25 or over 42

Same-sex couples may also struggle to access funded IVF treatment as they will be required to self-fund 6 cycles of IUI at approximately £1,000 per cycle plus medication, prior to qualifying for funded IVF. If they do not have the financial means to do so, they may not be able to access treatment.

With no additional funding included to cover travel and accommodation, this may also create barriers for some. Residents of Jersey going through IVF do not know their travel date until 24 hours beforehand meaning that travel can often cost in excess of £500 per trip, per person.

5. How should the government prioritise the use of the £620,000 to ensure the most effective and fair distribution of IVF treatment to those in need including single women, LGBTQ+ families/individuals, those with disabilities and those who already have a child?

We understand that there are concerns surrounding how many people may come forward to access treatment and believe this to be the reason for the strict access criteria. However, looking at the numbers of IVF cycles undertaken from our travel bursaries, it would appear to us that the criteria could be widened to be more inclusive and still fall within budget. We believe that access should be equitable for all demographics and should at the very least follow NICE guidance, which this criteria does not.

There is clear NICE guidance for what would be considered more equitable in terms of providing funding for IVF and it makes balanced clinical and cost-effective recommendations. The guidance also provides a clear definition of what is considered a full cycle of IVF which includes the subsequent transfers of all additional embryos following a fresh cycle through subsequent Frozen Embryo Transfers.

Points to consider:

- The 2024 UK Women's Health Strategy committed to address fairer funding for same-sex couples and to put an end to the non-clinical criteria that prevents patients from accessing NHS treatment if they have a child from a previous relationship.
- Previous self-funded treatment - NICE recommends that previous self-funded treatment should be counted towards a full 3 cycles of treatment up to age 40 (1 full cycle for those aged 40-42) due to reduced chances clinically of success after 3 cycles. The current Government criteria however, is applying this same approach but to the number of cycles a person is eligible for. So for example, if a person aged under 40 is eligible for 1 cycle based on the proposed new means-tested criteria, but has previously self-funded for 1 cycle, then they cannot receive a funded round. There is no clinical argument to support this. It should also be noted that people have had no choice but to self-fund up until now yet are being penalised for doing so.

- Criteria for single people and same-sex couples - if a same-sex couple can receive funded treatment following a demonstration of need through unsuccessful IUI/artificial insemination, why is it that a single person cannot, given that they would be demonstrating the same level of need for the treatment?
- NICE guidance does not stipulate that those who have previous children should not receive funding. To the contrary, it references that IVF is more effective in women who have previously been pregnant and/or had a live birth.
- BMI - NICE outlines guidance in terms of the ideal range, rather than stipulating that people should not be treated outside of this range. This is the same for ovarian reserve. The current proposed criteria is setting these as a cut-off for treatment - could these factors be considered on a case by case basis to determine the possible impact on the individual outcomes, rather than a set cut-off?
- The Government proposed criteria caps the number of transfers of frozen embryos per cycle at 2. It is a negligible number of people who will have more than 2 additional embryos to freeze/transfer following a fresh cycle and it raises questions around whether this is a necessary stipulation when taking additional administration costs to monitor this into account. NICE guidance defines a full cycle of IVF as one that comprises the transfer of all resultant embryos.
- Excluding funding for those who have confirmed genetic diseases - consider the implications this could have not only on the individuals in that position, but on any child born following the denial of treatment should their parents have been unable to self-fund. Also consider the potential greater costs associated with supporting that child throughout their lifetime. Where a disease is preventable should it not be possible to eradicate that risk?
- NICE guidance for fertility treatment is due to be updated in 2025.
- Take into account what other European countries are offering, not just the United Kingdom. As an example, earlier this year Poland reinstated state funding for IVF. Their new criteria includes funding up to the age of 42 with no ovarian reserve cut-off where women are using their own eggs. Funding up to the age of 45 where donor eggs or embryos are being used. It covers up to 6 cycles of IVF including a maximum of 4 with own eggs, 2 with donor eggs and a maximum of 6 with embryo adoption. For a clear overview of what is provided elsewhere in Europe you can view the European Atlas of Fertility Treatment 2024 (Jersey is included on this). It outlines what would be considered a "perfect" country (this includes up to 6 cycles of funded IVF and 4 cycles of funded IUI) and demonstrates where each country sits on that scale. The atlas can be viewed here:
https://fertilityeurope.eu/wp-content/uploads/2024/06/FERTIL-Atlas_EN-2024-JUN17.pdf

6. To what extent do you consider this funding will significantly reduce the financial burden on islanders seeking IVF treatment?

For those who qualify for the full three cycles, this will significantly help to reduce the burden. For those who do not qualify at all, the burden will increase as they will now be required to fund their medication costs in addition to treatment and travel. We have demonstrated that the restrictive access criteria will result in lots of people missing out and being worse off.

Our cost of living and IVF impact survey in 2023 demonstrated the significant financial hardship that undergoing IVF has on almost all going through it, even on those with a higher than average income. We have attached the results of that survey for you which clearly demonstrated the difficult financial choices people are having to make, including selling properties or foregoing the chance of ever taking a step onto the property ladder. We are also aware of people who have left the island due to the lack of funding available for IVF, combined with the high cost of living impacting on their ability to self-fund treatment.

7. In your view, what additional support measures could complement this funding to make IVF more accessible?

Consideration of the associated travel costs alongside re-thinking the removal of funded medication for those who do not qualify for full IVF funding.

Where BMI is being cited as a restricting factor, has it been considered what support could be offered to those being turned away for treatment? Many medical conditions, for example, PCOS can make it harder for those suffering from them to lose weight or maintain a lower BMI. Will these people simply be refused treatment, or will there be any support measures in place to help them achieve a lower BMI if this is deemed necessary for treatment?

It is worth noting again here that there are many aspects to the criteria as outlined above, that mean as it currently stands, that IVF funding will remain inaccessible for the majority of people.

8. What impact do you expect this funding allocation to have on the emotional and mental health of islanders struggling with infertility?

Facing a fertility struggle takes a huge toll on the mental health of those going through it. Our research found that 69% of respondents to our mental health and wellbeing survey who were struggling to conceive, reported feelings of depression. Further to this, 88% felt anxious and 6% suicidal as a result. A Fertility Network UK survey reported 42% of their respondents experienced suicidal feelings due to their fertility struggles. While 75% of those responding to our Cost of Living and IVF Impact Survey felt that their mental health had been negatively affected by the rise in cost of living, specifically with regard to how this might impact on their ability to pay for IVF.

Receiving funded IVF will not eliminate the pain of facing a fertility struggle, but it can help ease the burden and take away the additional worries associated with having to pay for treatment. It may also shorten the experience for many, as with funding available they may be able to access the treatment they need in a shorter time frame, lessening the amount of time spent waiting for a positive outcome and experiencing the negative impacts this has on their mental health.

Unfortunately for those who do not qualify and will also find themselves without funding for medication, this funding allocation may have a negative impact on their mental health due to additional expenses incurred and perceived unfairness of the criteria.

9. In your view, what are the long-term benefits of providing government-funded IVF treatment for the wider community in Jersey?

It has been widely publicised that Jersey has a looming population crisis. With a Total Fertility Rate (TFR) of 2.1 needed to maintain a population, the island's TFR currently sits at 1.32 and has dropped over the last decade. We understand this to be the equal lowest in Europe and 6th lowest in the world. The island's birth rates have dropped over the last decade and remain well below the UK average. Providing government-funded IVF would not only help towards increasing the island's birth rate, but it would also send clear a message that the island is family-friendly, recognises the importance of being able to build a family here and that it will support islanders in their time of need, making it a more attractive place to live and work and contributing to the retention of younger people on the island.

10. Are there any gaps or challenges you foresee in the Government of Jersey's approach to IVF funding that might limit the success of this initiative?

The Government of Jersey's Common Strategic Policy for 2024-2026 commits to delivering the best outcomes for islanders including ensuring that healthcare and support can be targeted to those who need it most and that people can access the right treatment when they need it. However, the strict criteria stipulated for IVF funding raises a number of questions and limitations for islanders who need access to the medical treatment.

While it is a positive start that more accessible funding is now being considered for IVF, there are certain further questions and gaps that the strict criteria highlight when it comes to allocating who receives that funding. These are strongly demonstrated within the responses to our IVF eligibility survey and in our response to question 5 above.

By limiting access to treatment for certain demographics without clinical reasoning, it may mean the difference of whether they can undertake treatment at all, resulting in fewer children being born on the island and significant impacts on the health and wellbeing of islanders facing barriers to accessing fertility treatment.

11. How might these challenges be addressed to ensure the funding reaches those who need it most?

For funding to be fair and equitable, it should be clinically based. Infertility is classed as a disease by the World Health Organisation and it should be treated as such and in the same way any other disease would be funded and treated in the island.

The government of Jersey's approach to "need" is something that should be reviewed inline with the above. A patient who needs a hip replacement for example, would not be expected to pay for this depending on their income. Someone who has had a caesarean for the birth of their first child, would not be told they would be required to pay for any that may be required in the future due to the fact that they have already had one child this way.

Fertility treatment should be put into context with other medical conditions and not be viewed as something people have a choice whether or not to undertake. The inability to access treatment may not be life-limiting, but the consequences are in no doubt life-altering and long-term.

This funding review provides an excellent opportunity to seek wider expert opinion from outside the island to come up with a robust and forward-thinking funding model. Tiny Seeds can help with providing contacts to both UK and European industry professionals who have offered their support with this.

12. What further steps should the Government of Jersey take, beyond this funding, to support islanders dealing with infertility?

Looking at the results of our eligibility survey alongside the proposed criteria, we hope that further consideration can be given and that on further review, changes may be made ahead of the introduction of the funding in January next year to allow greater access for those who need it.

It is positive to see that the provision of counselling services is being included in the funding, it is unclear whether this is to be available for all patients of the Assisted Reproduction Unit, including those who are privately funding treatment, or if they would need to pay for this service in addition to their treatment. We would hope that given the emotional toll a fertility struggle brings, that this will continue to be available to all.

Accessibility of off-island clinics is also an important factor, taking into account travel time and costs to get there.

Workplace support/statutory rights for those undergoing fertility treatment.

Review of laws in relation to donor conception, donor register and lack of ART laws currently on the island, particularly if ever considering opening a stand-alone IVF clinic in Jersey. However, this still applies now to those using artificial insemination using donor sperm on the island. There is currently no donor registry, or cap on the number of times a donor can be used in Jersey.

IVF Funding - Eligibility Survey Responses

Following the release of the proposed new Government funding criteria for IVF, Tiny Seeds released a survey to gather data on the impact that this proposed funding could have on those who need access to the treatment.

Participants were asked to respond if they live in Jersey and:

- have already undergone IVF and hope to undergo treatment again,
- plan or hope to undergo IVF soon, or
- have been advised that they need IVF treatment, but do not currently have the means to pay for it

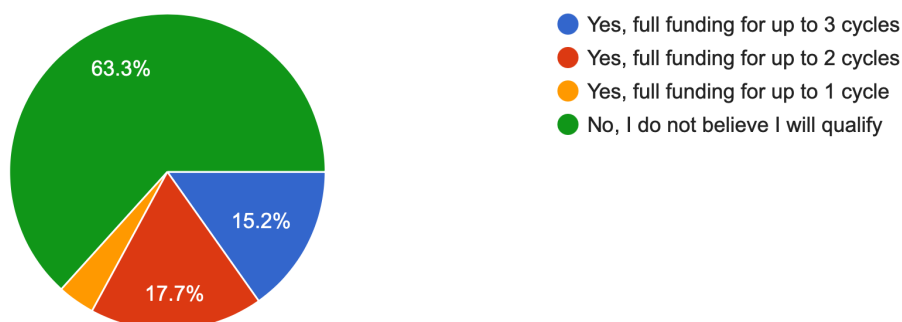
Participants were made aware that the results of the survey may be shared publicly and with third party organisations where it is deemed beneficial to do so, including Health and Community Services and the Government of Jersey. They were informed that they could skip any questions they did not feel comfortable answering and assured that the survey was anonymous and any comments made that were considered to be possibly identifying would be redacted before the results were shared.

Respondents were asked to read through the proposed Government criteria in full before responding to this survey with a link provided to do so.

80 responses were received and the full results are shared below:

Based on the Government's proposed new criteria, do you believe you would be eligible to receive funded IVF treatment?

79 responses



Yes, full funding for up to 3 cycles = 15.2% (12 respondents)

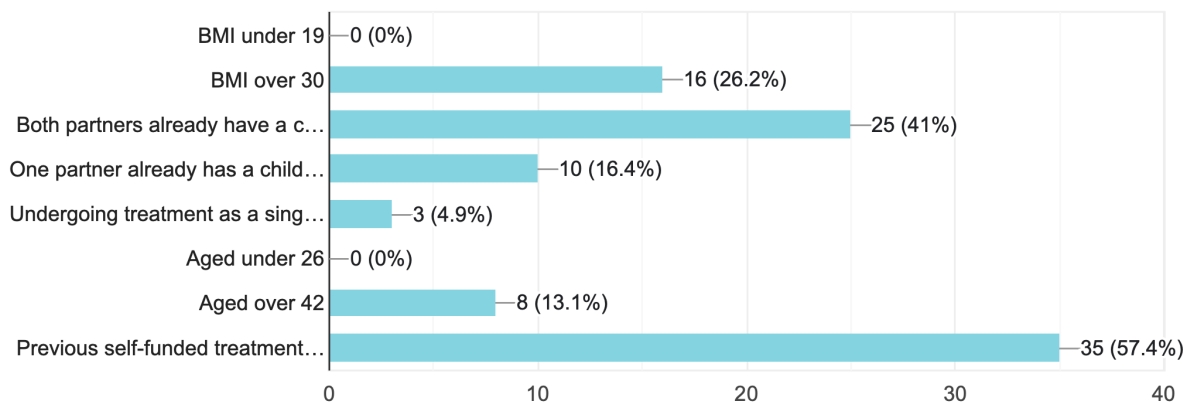
Yes, full funding for up to 2 cycles = 17.7% (14 respondents)

Yes, full funding for up to 1 cycle = 3.8% (3 respondents)

No, I do not believe I will qualify = 63.3% (50 respondents)

If you believe you would not qualify for funded IVF, please tell us which criteria limit you from doing so? (Please select all which are relevant to you)

61 responses



Where there are words are cut off in the chart above, these criteria are:

“Both partners already have a child or children”

“One partner already has a child or children”

“Undergoing treatment as a single person”

“Previously self-funded treatment cycles”

If there is another reason not stated above that you believe would exclude you from funded IVF please let us know here:

Yes low ovarian reserve and my partner has severe low sperm

N/A - 29 years old, PCOS and hormone imbalance affecting ways to loose weight.

Not living with partner for 2 years. How do they check this?

Not lived with partner for 2 years

Have difficulty getting pregnant due to thyroid issues and hormonal imbalance. Got pregnant twice but baby loss at 16 and 18th weeks. Not able to get pregnant even when labs are fine after 1 year of trying after the baby losses.

My boyfriend of 13 years has a 17 year old child from a previous relationship, I'm the one with the problems so not being able to get help for funding is so unfair.

Same sex relationship

Previous successful ivf child

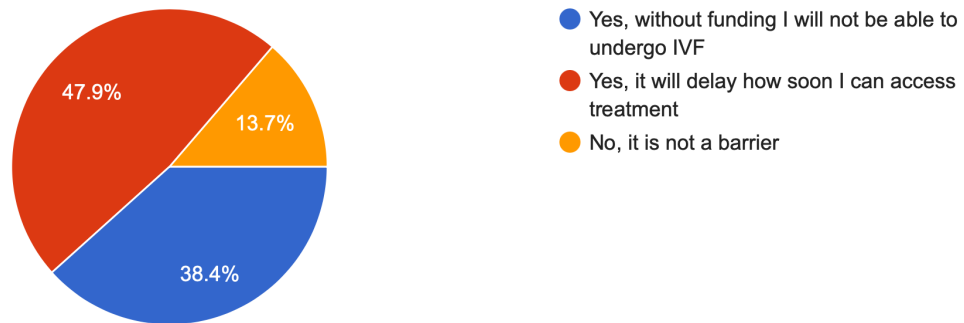
We have after 3 years finally had a successful round and I'm due any day now. But I believe I will still need to fund FETS for any future transfers

Might think that for my age I'm not ready but I'm 25

What is trying for 3 years and had one miscarriage at 6 weeks half way through trying

If you do not qualify for funded IVF, will this be a barrier to you accessing treatment?

73 responses



Yes, without funding I will not be able to undergo IVF = 38.45 (28 respondents)

Yes, it will delay how soon I can access treatment = 47.9% (35 respondents)

No, it is not a barrier = 13.7% (10 respondents)

Please use this box to share any comments or feelings and anything else that you feel is relevant or important, in relation to the proposed IVF funding and your own personal situation:

It is disappointing that we had to self fund our first cycle of IVF, but because it was successful and we now have a child we do not qualify for further funding. I am not sure why those who already have a child and have paid for IVF are being penalised. I realise that this follows the U.K. model, however I understand that the charity Fertility Network UK are lobbying the U.K. government to change this.

Being penalised as 2 x self funded with no success. Already spent thousands with unsuccessful rounds and government won't help. Really disappointing and unfair given the trauma already experienced. More tests have meant ready now to go but at almost £20k spent already sad we don't get a look in from the government.

We are not the main carers and they are my male partner's children from previous relationship.

BMI calculation do not necessarily reflects how healthy or not you are. Some athletes often have a high BMI even though they are not overweight. Late discovery of fertility struggles added to a "diet" would delay access to IVF and therefore may classify you in other category that would disqualify you to the funded program.

With a declining birth rate in the island it would make sense to support all islanders that are keen to have a child. To blanketly exclude single people who will definitely need fertility support in order to be able to have a child seems both unfair and detrimental to the islands need for more children to be born. It is also ageist to say that a male partner can be up to 54 but the female has to be no older than 42. Whilst traditional ivf rates may fall after this age, there are alternatives (donor eggs/embryos) which have also been excluded from this funding model but actually have a high success rate. I would suggest that the people drafting and voting on this funding strategy need further education on the

whole world or fertility treatment which it seems only those people that find themselves needing treatment do.

I am due to undergo my first IVF cycle next month. I have recently been diagnosed with stage 4 endometriosis, with one blocked fallopian tube. I have had surgery and we have tried to conceive naturally but we have now been advised to undergo IVF. My concern is that in the future I would not qualify for IVF if I wanted more than one child under the new proposed IVF funding.

Secondary infertility is a real medical condition and we are gutted we have been excluded

It would be beneficial to also be funded through the Women's Health Hub, not just ARU due to the high demand which will lead to lack of resources if everyone moves down that route. There is likely to be more demand than ever as people who have considered it for years but it's been unaffordable, will now be stepping forward and joining ARU.

Although my BMI being over 30 means that as a couple we will not currently qualify for funding this wouldn't be a barrier for treatment as we would pay for this ourselves. However, this wouldn't be £4.5k as noted as an estimate on the website, the cost of our privately funded cycle (1x fresh transfer & 1x frozen) was £10k. We have just enough savings to cover this privately ourselves but that is all that is left of our lifetime savings. These savings were meant for covering bills when I would hopefully be off for maternity leave. Using our savings to fulfil our dream of becoming parents leaves a black hole and further additional stress and worry about our finances.

Regarding BMI, having gained weight during previous hormone treatment during previous cycle I feel the criteria is too restrictive. The doctors we have spoken to have assured that given my AMH levels are so good for my age they aren't concerned about a BMI of 35 and that this is mostly a factor in consideration of any surgery undertaken ie a risk factor in being put to sleep for any reason not just egg collection. There isn't BMI restrictions for other medical treatment for illnesses so inflicting this on infertility couples again adds more pressure and stress on woman that will feel forced to lose weight for financial reasons outside of their doctors ensuring them it's not a factor in their personal infertility situation.

Do not feel support from doctor always a barrier for treatment

It's been challenging to self-fund, so finding out that it's now a barrier to support in funding is disheartening. I feel more disadvantaged by these criteria. We have unexplained infertility and worked so hard, making lots of sacrifices to be able to have a family. Having no support makes us feel alone and frustrated that our government has put criteria that disadvantage many. I don't believe this meets the NICE criteria which we should be following which will allow more support for a wider range of couples.

We are a couple just turning 40, my wife was 40 in July and I turn 40 next year. We have self funded 2 cycles previously, which were not successful. It feels very unfair that our ability to access funding for our next cycle is affected by previously paying ourselves, the treatment is expensive and we had to make compromises to afford the previous treatments, this element of the strategy seems very unfair.

BMI is such an old tool, for seconds I was so happy I would be able to have the treatments until I saw that I must be under 30 BMI, I struggled with weight all my life due to hormone imbalance, which isn't my fault and such things should have exceptions for if signed by the doctors, my GP is more than aware on this weight/hormone battle, it just super unfair as you see many healthy women getting pregnant twice if not more my weight.

The removal of funding for medications for all treatment will end up costing us more than it already does and could therefore delay any further rounds of ivf

As a same sex couple we have no choice of how to grow our family.

If I wait to be living with my partner for 2 years then I will be almost 40 and therefore will move into the 40-42 age bracket.

Based on what I've read. We will have to wait another year to qualify for 'living together' for two years. Which will bring me up to the age of 42. I do not understand why this is a requirement as it certainly doesn't confirm stable relationship status. I feel this needs to be reviewed

Loosing two children at 18th and 16th week was the most horrific trauma of my life. I went into deep depression after it. And then even being seeing in ARU and going cycle after cycle and not able to get pregnant has taken a big toll on my mental and emotional health. I am a software engineer and wanted to progress in my career but due to the trauma and the emotional and mental toll I'm not even able to focus on my career. I feel that life has stopped and I'm stuck. I'm afraid to again go in deep depression due to all this. I wish I can be helped to have a baby. My husband is such a nice person, he lost his father this year and he too lost his children, some days he has to stay at home to take care of me if I'm disturbed mentally or emotionally. I can see how much all this has affected him. I wish someone can help us. ARU has told us that IVF is the only next step. I just wish we are helped soon.

Feel very penalised for already having funded a successful round of IVF ourselves meaning that we would not be eligible for government funded IVF. Would have been nice to even have funding for transfer only side of things seeing as we have already paid the bulk of it already

We used all savings and borrowed off family for previous treatment. We simply could not afford to do it all again and have to accept our child will never have a sibling.

Although a great step in the right direction, the 8 months between announcement and potential effect means we have had to start our first treatment in the meantime as age is a deciding factor.

It is a reassurance in case it goes wrong, that two cycles are paid for, however given it won't apply for a second child, we may find ourselves financing a successful first round and any subsequent treatment (whilst potentially navigating the expensive cost of childcare on island)

I don't believe the government should limit the amount of cycles that a couple are eligible for based on their income. The fully funded 3 cycles should be mandated regardless of this. My partner and I have self funded 5 IVF cycles, 4 frozen embryo transfers, paid for egg storage for the last 5 years, on top of self funding all our travel, accommodation, medication, multiple tests and biopsies which has incurred costs which are outrageous. We have used savings which we no longer have, and our salaries simply keep our mortgage payments up and keep us afloat.

I will not be able to afford a house to buy in jersey having to use all my savings

It would be a great help if IVF will be funded especially to those who don't have the means of doing it.

Unfortunately IVF is not something we can just afford to go and do we have to save up for it and I'm unsure how long that will take and at the age of nearly 39 time is not on my

side. We had to have fertility treatment for our first child due to pcos, underactive thyroid and endometriosis. Thankfully the first time round we didn't need full ivf and were able to conceive after some time on medication and injections. This has not been offered this time and we've been told our only option is ivf.

I don't think this is fair. We paid for IVF so we should still qualify for 1 free round under the new scheme. I feel we're being discriminated against for wanting a second child.

As we used all our savings on our first child when no funding was available we now can not get any funding which seems unfair.

I feel the government criteria will discriminate against women over a certain age, and households where blended families are very common.

It will not delay our treatment because we have already budgeted for it, but it means that we have compromised on much needed holidays this year, renovations on the house, buying furniture which we need, and buying a second car to help with family logistics. All of these have been postponed indefinitely to be able to have treatment soon.

People with children already should be able to get help for funding even if it means there be a limit on how many children you have already or the age gap.

Personally, we're in a strong financial position that means the government funding doesn't impact our decision to have more IVF should we need or choose it.

That said, the funding is a positive step forward but I think the government needs to increase funding and consider the long term impacts of 'limiting' children born each year for the economy and Jersey's future.

To sustain the global population, each female needs to have 2.1 children- with infertility on the rise, and the cost of living putting severe pressure on people's decision to have children I think the Jersey government has an opportunity to do everything it can to look after the future population by expanding the rules for who is eligible. If couples have been through a self funded round, have a child or one parent has a child then I believe they, along with single prospective parents should have more funded access to IVF.

On a human level I think that would be fair but on an economic level it's a sensible direction to support the future generations of Jersey.

I have a few medical conditions that don't help me to conceive like endometriosis and pcos

It is not only the cost of the treatment that is an issue. Travel to and from the uk as well as having to spend a week away from home, work and pets. All of which needs to be taken to consideration logically as well as financially.

I do not think the full 3 cycles should be means tested. There shouldn't be any discrimination in what the Government offer in terms of helping combat infertility. It is wrong to offer to treat one, to the best of your ability, and not another solely because they have more money.

Cost of living and declining birth rate should be considered. If it is the intention to encourage young couples to stay on island to build a family, then the Government need to be seen to be supporting those couples and investing in the future of the island through them.

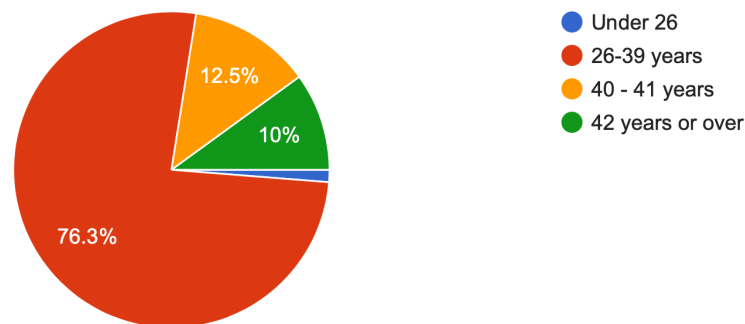
People shouldn't be rejected because of weight as some weight issues are not lifestyle choices but health conditions

We had three miscarriages and then a baby. I would therefore not qualify for IVF in future.

I think it's important for people like me to get a chance at having a child without having to pay extortionate prices

What is your age (age of female undergoing, or hoping to undergo IVF)?

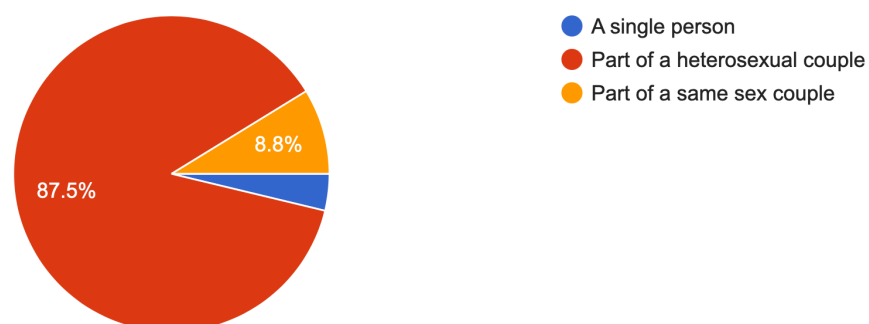
80 responses



Under 26 = 1.3% (1 respondent)
26-39 years = 76.3% (61 respondents)
40-41 years = 12.5% (10 respondents)
42 years or over = 10% (8 respondents)

Did you undergo or do you plan/hope to undergo IVF treatment as:

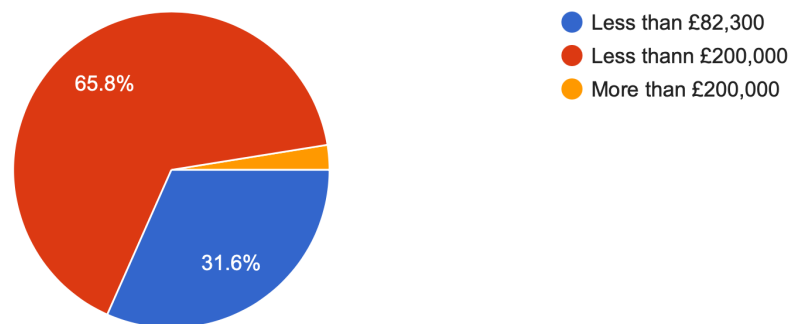
80 responses



A single person = 3.8% (3 respondents)
Part of a heterosexual couple = 87.55 (70 respondents)
Part of a same sex couple = 8.8% (7 respondents)

Please could you tell us your gross household income? If you underwent or plan to undergo treatment as part of a couple, please tell us the combined total:

79 responses



Less than £82,300 = 31.6% (25 respondents)
Less than £200,000 = 65.8% (52 respondents)
More than £200,000 = 2.5% (2 respondents)

Please share anything else that you feel is relevant or important here, including any changes you would like to see made to the proposed new government funding for IVF:

Secondary infertility is unfortunately very common, don't feel you should be disqualified if you already have a child

I feel like the band from 82000 to 200000 is a huge jump for gross household incomes. Me and my partner earn 85,000 between us so we will miss on one cycle for 3000 when the jump is to earn an extra 118,000

Fertility issues is a struggle, a complicated journey and often feels like a battle against your body and time. Despite the amazing progress with funded IVF treatment, I do feel that I would have to go through an administration battle as well to get an application accepted without the certainty of a positive results at then end.

I feel that each patient or couple should be treated as an individual, with their full situation weighed up and funding provided based upon the impact this funding could have on their chances and what it would mean to them to become a parent. As a single person I have already had to go to extraordinary lengths (sold my flat, used all remaining savings) to be able to afford the treatment that I have had but sadly due to covid and then issues with the clinics (not my health) I have still found myself without success. I desperately hope to try again with another round of treatment (donor embryo) but will all depend on how I can manage to save the money in time. I have had many people tell me what a wonderful parent I would be, but as a single person wanting fertility treatment this is not taken into account at all within the current or proposed funding system, which I think is a real shame for me and the potential future child that I could have. I am Jersey born, educated and have lived here my whole life but with the high cost of living here it is only now that I would be in a position to afford to support a child. I have always paid my taxes, social security and worked for the local government for the last 15 years, but none of that entitles me to any financial support at all on my journey to become a parent.

I really hope that this funding model is expanded and there will be far more understanding within government of the difficulties (financial, physical & emotional) that

patients undergoing fertility treatment face. It is still seen by many as a 'luxury' which is so very far from the truth and reality, which if known would probably horrify a lot of them. The many, many tests, doc appointments, treatment research, weighing up options, £000's, no alcohol/processed foods, daily injections, raging hormones, waiting for weeks/months/years, finding out it's all been in vain, having to go through it all over again numerous times. Does that sound like a 'luxury'?! I have even had it suggested that I should just 'go out to the pub and have a one night stand as it would be cheaper'wow, just wow. Is that what we want to tell our future generations as to how they came to be?! I honestly hope not.

If you are experiencing secondary infertility to be able to still receive funding.

I think it's a great start! Although we have above average salaries, they're not going up in line with inflation, mortgage rates are through the roof and we pay circa £40,000 in tax per year between us so saving for IVF has been impossible.

It would be beneficial for everything to be included. The article suggested it's circa £5,000 per round although from research and talking with multiple people who have been through it, the average cost of an IVF cycle is £15,000 therefore, there's either a lot not covered still or the information is inaccurate.

Although this isn't my personal circumstance, I don't think it's fair for couples with a child from a previous relationship to be denied treatment. There are women/men desperate for children of their own that will not qualify. It shouldn't be built into government policy how many children are 'enough' children.

Always helps people no matter income

I would like to see these restrictions being reconsidered so that funding is accessible to more of the community struggling with fertility. I feel there is a high inequality with this criteria.

Support around travel costs would be appreciated, the process is hard enough already, exaggerated by living on an Island and the rush to get to a treatment centre in the UK after a scan. From our perspective, as a couple who have previously self funded, the impact of funding previous cycles on accessing funding is frustrating and feels discriminatory.

This is a great first step, and I'm happy for everyone this will help. It's just a shame that it comes with the regression of medication costs so even though we don't qualify for help, it will become even more costly than it was before

I think everyone should be entitled to financial support / funding for ivf regardless of situation

Should be for everyone

I believe potential single parents should be eligible.

I believe families who have children already should be eligible.

What support will you give couples made of 2 men

People with a uterus who have fertility issues of their own or in a couple and already have a child should be eligible.

Couples should be supported to have more than one child.

I paid for my own egg freezing, while I was single, knowing that I would have issues with falling pregnant in the future and wanting to freeze my eggs while I was younger. I think egg freezing should be funded for at least 1 cycle especially for females who will have problems conceiving.

The criteria of trying for 2 years, I think it's not fair to make someone go through this pain for so long. Or trying other treatments before IVF when you clearly know that they will not work.

To have funded IVF for more families in Jersey regardless of how many children they have and whether they are self funded round before.

Mandate 3 fully funded cycles regardless of income, a couple goes through enough emotional and physical stress when going through IVF

Do not make people now pay for medicines for secondary infertility you are making it more expensive

To help fund egg donation alongside IVF

Is it possible to freeze multiple eggs before starting one cycle of IVF/ICSI treatment? Can this be funded or part of the government funding?

If a couple previously needed fertility treatment they should be entitled to have at least a couple of rounds of IVF secondary infertility is a thing! How can a couple be living here for 12 months be entitled, but not someone who already had a child. It's madness. Then to top it all off if you don't qualify you won't receive any help at all in terms of appointments and medication.

I think everyone should at least get 1 round of IVF free under the changes no matter of their circumstances.

I feel it's unfair if you or either parents has any prior children, each person should be entitled to funded rounds irrelevant of prior children.

I think that people who have self funded and meet criteria should also be entitled. People shouldn't be penalised when they have struggled to self fund. Thank you for all of the work you do!!

IVF is such a unique multi layered process, and should be based on individual needs, whilst I think it's great that the government are potentially stepping in, infertility affects all people from all walks of life for lots of different reasons. The cost of going off island, time off work all adds up, and incorporating this into supporting those on their journey needs to be given some further consideration. Thank you for raising this with the government and getting the conversations moving

More inclusive eligibility criteria, or at least allowing those with proven infertility access to funded treatment, whether primary or secondary, or irrespective of sexual orientation or relationship status.

Everyone should be given the opportunity to have a child

It's a good step forward but the rules are too narrow. From what I've learned about people going through IVF, is that these are people who are desperate to be parents, and should probably be the portion of the population having more children than most.

More help for people with medical issues

Medication costs if self funding, I don't understand why this has now been removed

I have had a successful previous ivf round paid by myself and my partner. I am now 41 and have two embryos remaining. Will this be funded? Also bmi 30 seems quite low and i do not agree with bmi testing as you can be fit and healthy and over 30 bmi.

As someone who has been trying for a baby naturally for 2 years, has been referred to the ARU for assistance, and now has finally been referred for IVF, what I would also like to see is better support in the workplace for those struggling with infertility.

I was placed on letrozole, a fertility drug with side effects that made it near impossible to focus and left me feeling quite awful. A necessary step, but one that made working difficult.

There is a fear around women revealing that they are trying to conceive as often, in workplace environments, you are then considered a liability. Passed over for promotions because you will be "out of action" for the better part of a year. So women tend to have to go to work, while feeling a whole host of uncomfortable and painful things, and be expected to "just get on with it".

I think the government should still help with medication if they won't assist with the actual treatment for those who don't qualify based on the criteria they have set out

We have spent years funding egg collections and FETs although I'm happy treatment will be easier for others going forward it is disheartening that if we want to try for another child we will still have to fund and have the financial restrictions

It should take into consideration couples who have had a baby before. It totally disregards out three other losses and could mean more loss for us which makes it scary to try again even though we want to grow our family.



THE COST OF LIVING AND IVF - IMPACT SURVEY 2023

The Cost of Living and IVF - Impact Survey

Conducted by Tiny Seeds - fertility support and awareness charity - 2023

Introduction

The World Health Organisation (WHO) defines infertility as a disease for which in vitro fertilisation (IVF) is widely accepted as a primary treatment source. Infertility is not the sole reason for undergoing IVF and the treatment is also used by same sex couples and single people who are hoping to build their families. Access to IVF in Jersey is on a predominantly private basis and is a high cost treatment, often requiring multiple cycles as well as incurring additional costs such as travel and accommodation.

This survey was designed to examine the impact that the financial implications of IVF and the high and rising cost of living in Jersey have on those who require IVF treatment in the hope it will help them to build a family.

In 2022, 107 cycles of IVF were facilitated by Jersey's Assisted Reproduction Unit for 62 unique patients or couples. This survey was circulated widely on social media to the Jersey community and 56 responses were received from people who:

- have undergone IVF within the last 18 months
- hope or plan to undergo IVF soon
- have been advised that they need IVF but currently do not have the means to pay for it

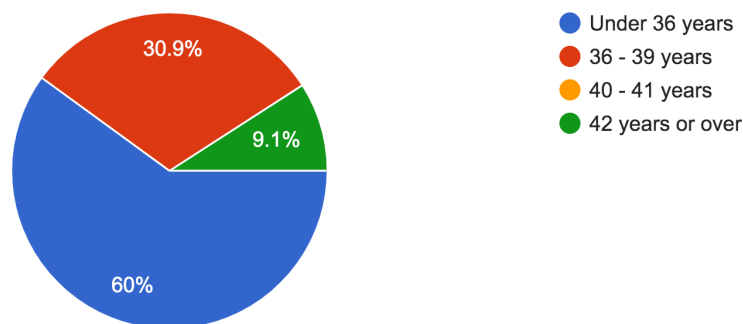
Key findings from the survey are summarised below.

The demographic of those undergoing IVF treatment

The age brackets of those undergoing IVF are shown here:

What was your age (age of female undergoing IVF) at the time of commencing treatment?

55 responses



84% of all respondents were undergoing IVF, or hoping to undergo IVF as part of a heterosexual couple. 7% were in a same sex relationship and a further 7% were undergoing treatment as a single person.

The majority of respondents (71%) lived in an owned property with an outstanding mortgage. 23% lived in private rented accommodation with a further 2% in Government rented accommodation and 4% in family/family rented properties.

Accessing Financial Support

As at May 2023 in Jersey, if a couple undergoing IVF treatment has a joint annual income of less than £34,130 they would qualify for their IVF treatment to be fully funded for up to 3 cycles (subject to meeting further eligibility requirements). A joint annual income of between £34,130 - £40,795 (again subject to further eligibility requirements) would qualify them for full funding for up to 3 cycles subject to a nurse admin fee of £220.

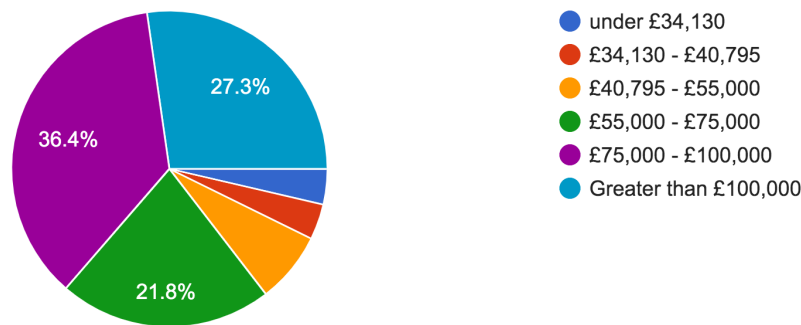
Medication costs for up to 3 full cycles of IVF are currently funded for all those in a relationship under the age of 42. This equates to approximately £1,000-£1,500 per cycle of IVF. The starting cost for a full IVF cycle excluding medication, is approximately £4,000. For those that are successful it takes on average 3 full cycles.

Those undergoing fertility treatment as a single person do not qualify for funding and are required to meet all costs associated with their treatment including medication.

Of the 56 people who responded to our survey, just 4 (7%) fell into the bracket that would provisionally qualify them for full funding/full funding subject to the nurse admin fee:

Please could you tell us your total annual salary? If you underwent or plan to undergo treatment as part of a couple, please tell us the combined total.

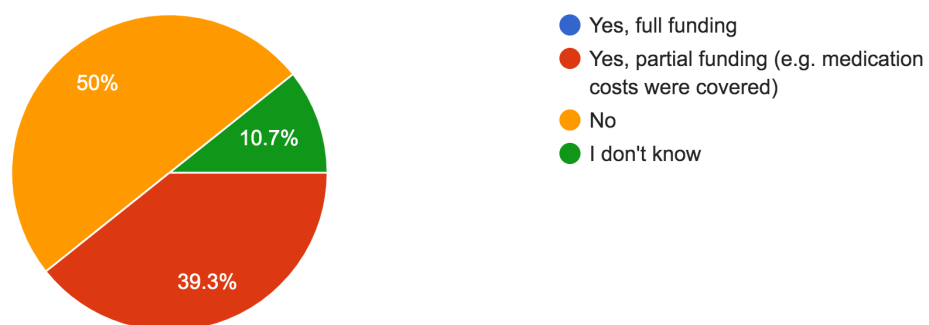
55 responses



However, not one respondent stated that they had received full funding for IVF:

Were/are you eligible for financial assistance to pay for, or to help towards, your IVF treatment?

56 responses



Looking at their individual responses, this could be down to a number of reasons; they did not fit the further eligibility criteria, they have not yet undergone treatment, or they were perhaps unaware or not informed that they qualified for funding.

Financial Implications of needing IVF

The average amount our respondents had spent on treatment up to the point of completing the survey was £15,011, with a further £2,678 spent on travel and accommodation costs associated with accessing IVF clinics away from the island. In total, this equates to an average spend of £17,689. These figures are in addition to, not inclusive of, any additional funding covering medication that they may have qualified for.

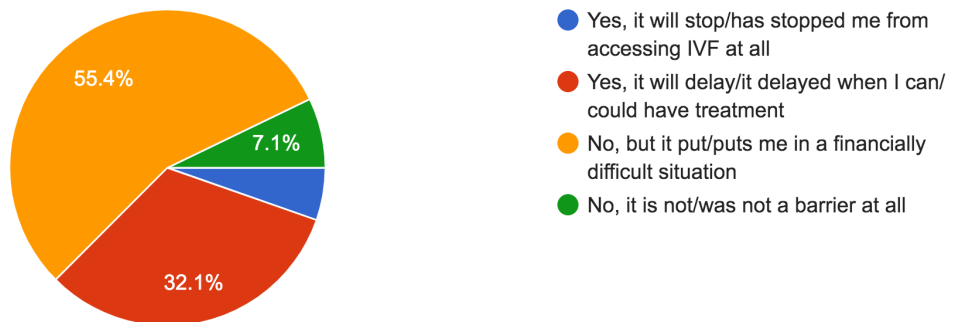
The percentage of those who responded who will require further IVF in the future, or who are currently still unsure of this, is 87%. Just 13% stated that they will not require further IVF.

64% of all respondents shared that they needed, or will need, to borrow money to fund their treatment. This borrowing is from a varied but even spread between bank loans, credit card payments and family/private loans.

For 32% of people, the cost of IVF delayed or will delay, when they could/can access the treatment, with 5% of respondents unable to access the treatment at all due to cost.

Is/was the cost of IVF a barrier to accessing treatment for you?

56 responses



60% of respondents have had to make a choice between making milestone purchases or paying for IVF:

"We prioritised and spent the money for a deposit for a property on IVF. With our ages now and the high cost of housing, not sure we will ever afford a mortgage on island."

"I sold my flat to be able to afford fertility treatment and start a family. I am currently renting and my proceeds/savings are almost at an end."

"I can no longer purchase a house as my deposit savings have gone and I am having to downsize my rental to afford treatment."

"We were due to get married in May 2024 which was booked before we found out we would need IVF. We are now going to have to postpone this as anything we had saved towards the wedding went towards our first round of IVF and any future savings will be going into IVF."

"We can't afford to buy a property and if/when we go through IVF again for a second child we will have to borrow money to help us."

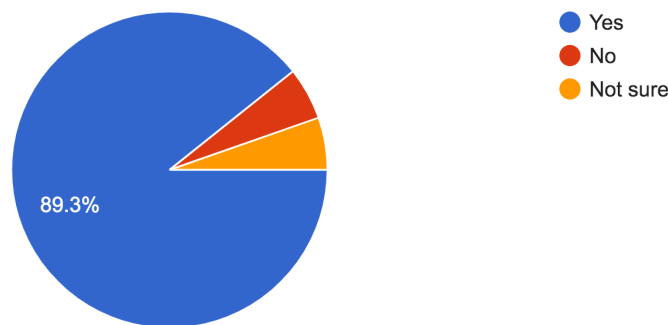
"It will mean staying in unsuitable accommodation to raise a family, but we can't afford IVF and a property move. And I don't have age on my side to be able to wait for IVF."

Cost of Living

89% of our respondents felt that the cost of living in Jersey negatively affected or will negatively affect their ability to pay for IVF treatment. With over 96% also stating that their mental health had been negatively impacted by the rise in cost of living, specifically with regard to how this impacted/impacts on their ability to pay for treatment (46% "a great deal", 29% "a moderate amount", 21% "a little").

Do you feel that the cost of living in Jersey negatively affected/will negatively affect, your ability to pay for IVF treatment?

56 responses



Further comments shared by respondents with reference to the cost of living in Jersey and how it is impacting on their ability to access IVF treatment included:

"Living in Jersey you always accept that you will need to pay more to travel for certain life events or to see friends and family. However costs such as monthly energy bills in an island where there is little to no choice of providers definitely affects if not our choice to undergo IVF, certainly our timescales of when we can afford to do it. Obviously in this type of treatment time is very crucial and success is lower the longer we wait."

"Paying for flights at the last minute for egg retrieval is expensive. The whole process was very stressful and impacted my mental health greatly (I am now on anti-depressants)."

"I used all my savings for our treatment and because of the cost of living increase I am worried about the future if anything goes wrong because we are now living hand to mouth."

"My husband and I have been saving to buy a house for 7 years. However, due to the housing market and lack of action from the States to build more affordable houses for first time buyers its meant we've never had an opportunity to buy a house. We'd always planned to buy a house before starting a family but, with the rising costs of rent and soaring house prices we've been constantly on the back foot. In the end we made the choice to focus on starting a family but, now we're going through the fertility struggle I wish we'd prioritised trying for a family much sooner and given up the hope for a home of our own a lot earlier."

“As a couple we both have well paid jobs and we have a house with a mortgage however the cost of IVF alongside a lack of salary increase to match the rising cost of living has left us doubting whether we can afford IVF. It is horrible to have to think of the money side of things but how can we empty savings/borrow money to go through IVF knowing that we would then be in a bad position should we be successful. The fact no IVF treatment rounds are offered free of charge in Jersey is so upsetting. I don't want money to be the reason we don't have children, that seems so wrong.”

Conclusion

This survey clearly demonstrates the very real impact that the cost of IVF combined with limited financial support available and high cost of living in Jersey, has on those who need access to IVF in the hope of building their families. This is not just a financial burden, the affects on the mental health and wellbeing of those undergoing or intending to undergo this process are also great.

A large proportion of respondents are on incomes equal to, or higher than, the 2022 mean average salary of £860 per week (Government of Jersey Earnings and Income Statistics 2022), yet 64% of respondents could not afford treatment without taking on debt. Respondents are seeking a wide variety of sources in a bid to find a solution to borrow the funds they require to progress with their treatment and a significant number of people are delaying their IVF treatment due to financial constraints. Those on lower salaries are highly unlikely to fit the means tested criteria for full financial support and may be unable to fund IVF treatment at all. Where IVF is going ahead, for many this is in place of other life milestone events, such as buying a property and in some cases it means foregoing the chance of ever making a step onto the property ladder.

What is clear from the results of this survey is that the cost of IVF in the current climate for the average Jersey citizen is a very real issue, impacting almost everyone going though the process and unfortunately these impacts are significant and often long lasting, both financially and on peoples chances of reaching life milestones.

For any enquiries or questions relating to this survey and its findings
please email hello@tinyseeds.je