Jersey Women's Health Hub – Reply to the Scrutiny Panel on the Proposed IVF funding budget

1. To what extent do you consider the proposed allocation of £620,000 for IVF infertility

treatment in 2025 is sufficient to meet the needs of Islanders struggling with

infertility?

2. Based on your experience, how many Islanders could realistically benefit from this

amount of funding?

The offer of some funding to islanders who are eligible is encouraging and an improvement on the current status quo, however whether £620,000 is enough to cover those eligible remains to be seen.

Currently infertility affects 1 in 6 couples, and these rates will increase as median age of mother's increases. According to the Human Fertilisation and Embryology Authority (HFEA) the average age of first-time IVF patients has increased to just over 35 years old. As infertility rates rise, as well as the age of patients the need for assisted fertility will become greater.

Currently in England 17% of IVF cycles are funded, their qualifying criteria is similar to that in Jersey but not the same, financial earnings are not considered instead more stringent use of serological biomarkers such as Anti Mullerian Hormone (AMH) and Follicle Stimulating Hormone (FSH). These medical tests give an idea of egg quantity, but not egg quality which is usually determined by maternal age. IVF success rates can now be predicted using calculations based on previous patients' data with similar demographics to the individual, chances of success depending on data may be a fairer way of proportioning funding.

It is difficult to know whether the amount quoted will be sufficient because we have not seen the data that was used for modelling. It has been decided to not follow the National Institute of Care and Excellence (NICE) guidance but rather adopt a unique means tested allocation, along with UK type 'filters' for access. It is our understanding that the average cost to a UK care commissioning group (CCG) for one cycle of IVF would be £3483, and so three fresh rounds would amount to £10,449 / couple, with the couple paying for travel and accommodation.

It does not appear to be known just how many couples each year would be eligible for funding, but from experience, it would be far fewer than 60 couples. If that is the case, and Health and Social Care (HCS) follows the proposed guidance as to who gets funded treatment, then there should be funds remaining for the drug costs for those having other forms of infertility treatment. We are concerned that these will not be funded, this will disadvantage those choosing not to have IVF and may also push those into IVF prematurely. When there is

a financial incentive to the patient to choose IVF over other options, they may feel inclined to proceed unnecessarily.

The current ARU management does not appear to follow the European Society of Human Reproduction and Embryology (ESHRE) guidelines with regards to the management of unexplained infertility for example. Couples with this condition, which may account for 30% of infertility, are currently steered towards IVF rather than Intra uterine insemination (IUI), which can be an on-Island treatment modality that was popular and often achieved good pregnancy rates. The local management of the infertile couple will therefore continue to dictate how many people will use IVF, and this further complicates the modelling process.

We also have concerns over the under investigation of couples with unexplained infertility, and are aware very few are currently offered laparoscopy in order to rule in/out endometriosis. Leading to both undiagnosed endometriosis and higher rates of IVF.

It may be beneficial to decide the approximate number of those eligible, and provide patients with an amount to spend at an IVF clinic of their choice, as couples will have a preference and treatment needs will differ. Around 100 cycles of IVF are undertaken each year in Jersey. According to our Jersey Women's Health Hub (JWHH) records we are seeing 30% of the overall work.

3. What are your thoughts on whether the funding allocation will provide equitable

access to IVF treatment for all those in need in Jersey?

4. Are there particular groups or individuals who might still struggle to access treatment

despite this funding?

Unfortunately, the funding allocation criteria does not provide equitable access to all those needing IVF treatment, and is at risk of appearing outdated at the time of agreement.

There will be many groups of individuals who will struggle to access treatment and notably these would include couples who have a child from any previous relationship. For example, consider a 36-year-old woman who has a child with a previous partner who died prematurely, now has a new partner, but his sperm count is so low that they require IVF to have a child of their own. They will ineligible for funded treatment. Or a 36-year-old woman, who meets a partner who has a child from a previous relationship, but her fallopian tubes are blocked because of previous appendicitis, and now requires IVF. They will be ineligible for funded treatment. There are many more examples that need considering.

We hopefully live on an island which values cultural variation, and at a time where personal relationships and family units look less nuclear. The current access criteria appear biased towards heterosexual couples and does not take into account the LGBTQ community. The process of becoming a parent for these individuals is already more difficult as the it almost always involves a third party. With this comes extra expense, which has dubbed

by some as the “gay tax”. Homosexual couples within the UK are eligible for some funded assisted reproduction on the NHS and not considering this may appear prejudiced. NICE consider that same sex couples should be funded for treatment. Should we include single women too?

We also live in a society where levels of obesity are increasing, using weight as one of the main exclusion criteria may reflect poorly. There are also other medical factors which may impact success of IVF more, such as ovarian reserve which would be more sensible to also include and would avoid appearing like this factor has been singled out. Why exclude a woman from funded treatment when she has a BMI of more than 30? IVF treatment is still successful in this group and for her to lose enough weight to get into the funded bracket could take years, by which time her egg quality has declined to such a level that her chances of success have significantly worsened. Is this ethically acceptable?

If certain lifestyle measures have been singled out as exclusion criteria i.e. smoking, weight- it may be necessary to offer support individuals with these issues to help them meet the required criteria. Those with a lower socio-economic status who are more likely to qualify under the means testing aspect of the criteria, but are more likely to smoke, and have higher levels of obesity. Some conditions which cause infertility such as PCOS, also cause weight gain, a variable which the patient will not have full control to change themselves.

We’re uncertain as to why the funding is means tested, everyone pays taxes and I do not know of another medical treatment use to treat disease where allocation is based on your earnings. We do not refuse transfer to the UK when you have had a heart attack based on earnings, weight, smoking status, quite the opposite. Issues of infertility are largely not lifestyle related.

Couples of lower socioeconomic status and non-English speaking residents notoriously struggle to access services. Whilst funding will help, even travel costs off island may be too much, as well as language barriers.

Treatment often involves staying in the UK for several days and having the freedom to choose a clinic which is geographically suitable may help.

<u>5. How should the government prioritise the use of the £620,000 to ensure the most</u>

<u>effective and fair distribution of IVF treatment to those in need.</u>

Funding should be prioritised to those who are more likely to achieve a live birth, using proven medical statistics using individualised medical data. By setting eligibility criteria in a factual rather than subjective manner i.e. chances of success according to age, FSH and AMH levels according to similar patient demographic, the reasoning behind it can be easily justified.

We’re not sure denying funding based on sexual preference, weight, earnings will be viewed as fair by the general public.

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

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

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

It is a good starting point, it will help the initiation of treatment, but I'm sure there will still be a considerable cost to couples. As previously mentioned, couples undergoing fertility struggles need to factor in the cost of travel, accomodation, time of work.

The funding will certainly help the emotional and financial burden of those who are eligible. There is a problem however for some, who are to be excluded if they have had IVF treatment before this HSC law comes in.

Education needs to be provided to health providers and also local publicity, involving local charities to help educate the public about access.

Some women, or couples, feel that they need an alternative provider to the hospital-based ARU, and it appears that around a third seek treatment through another on Island provider, the Jersey Women's Health Hub. If this provider is following best practice (inspected) and is linked to a HFEA UK licensed provider, then access should be permitted through this source too; with the funding following the patient. Indeed, it would perhaps be an idea to look at the provision of fertility care more generally, as much can be performed in the primary health care setting, with tertiary centre input, with evidence-based care pathways. The JWHH can carry out Hystero-salpingo foam sonography which is a tubal patency test currently unavailable in the HSC where tubal patency testing is only carried out using X-ray techniques, exposing women to radiation. We've had a number of patients who have undergone this procedure who have gone onto achieve pregnancy, and therefore avoided IVF.

9. In your view, what are the long-term benefits of providing government-funded IVF

treatment for the wider community in Jersey?

Apart from the moral argument, the provision of funded IVF will mean Jersey is no longer an outlier on the European Fertility Atlas. Apart from the obvious help to the local community, this is also important for some couples seeking to relocate to the island and planning their futures.

We have recent seen in Jersey the lowest birth rate in 2 decades and this is likely to be an escalating

problem. Fertility rates are currently at a rate which will not sustain our population number, an issue which will impact future generations as the proportion of working population declines.

Providing funding will mean families will carry less personal debt, many couples have large personal loans in order to undertake treatment. Having children born into debt at a time of soaring childcare costs is detrimental to our community.

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?

11. How might these challenges be addressed to ensure the funding reaches those who

need it most?

It would be useful to have the figures on how many couples would be eligible for funding under the proposed guidelines before deciding how far this approach will go to helping infertile people. We would hope that women who need fertility drugs, for non-IVF treatments would still be eligible for these free of charge, because whilst IVF may provide the best route to take statistically, women should be given the chance to explore non-IVF treatments where appropriate, following best practice guidelines. Having off island IVF is more difficult than if the patients lived on the mainland, with travel and hotel costs adding to the expenses.

There also needs to be a review of the non-financial aspects of what is required to be funded.

What does a stable relationship mean, and who decides if this is so? How will this be proved?

Having to be a resident in Jersey for 12 months prior to funded treatment seems harsh, when success rates are inversely correlated with the woman's age (egg quality). Maybe 6 months would be fairer?

The existence of previous children has already been mentioned above and this remains controversial.

To have funded treatment it is proposed that 'ovarian tests' will be carried out to see how the ovaries will respond. This is harsh because these tests may predict the number of eggs produced in a treatment cycle but not the quality of them and therefore the success rate. So, for example, if a woman has blocked fallopian tubes, and requires IVF, and her ovarian function test suggests an AMH of less than 5.4pmol/l (an arbitrary level used

often in NHS funding), this does not mean she will be unsuccessful as there is a big difference in success rates depending on age. For example, if a woman has a low AMH of less than 3pmol/l and she is under the age of 35 years her chance of having a livebirth on a single cycle of treatment is in the order of 32%, but if she is between 40-42 years of age her livebirth success rate would be only 11%. So why exclude a younger woman with poor ovarian reserve?

Why must the man be under 54 years of age? Paternal age does not correlate with success rates, or mean that a couple with an older male partner is less 'worthy' or parenthood?

The proposed policy states that the couple should have 'exhausted all other forms of treatment' before funding will be considered, and yet will not fund intrauterine insemination (IUI) which may well be an acceptable form of treatment that was available to women less than 40 years of age prior to 2021. Staffing deficiencies in the Assisted Reproductive Unit (ARU) and pathology laboratory and the relocation of ARU to Le Quennevais have hampered an IUI service and it seems unreasonable to make all have to pay for this? We regularly have inquiries regarding provision of IUI, this again disproportionately hinders homosexual relationships who now have to have IVF, or IUI off island, and additional unnecessary expense,

Whilst understanding the reasoning behind a complete ban on smoking tobacco, vaping and alcohol for example, one may ask why these limitations are not applied to many other areas of medical treatment?

The limits that relate to BMI are also interesting and it remains sad that our government is slow to limit access to ultra processed foods, two for one meal deals and sweets at the checkouts etc.

It may be sensible for allocation of funding to the individual couple rather than a single service, this is a cohort of patients who already feel helpless, allowing them to decide who provides their care will empower them. We are a small island, and this is our opportunity to provide funding ad a service which is better than, not below or equal to the NHS. Patients should have equal access to approved treatment providers, IVF is highly individualised and not one criterion will fit all.

12. To what extent could collaboration between public and private healthcare providers

improve access to IVF services in Jersey?

We would welcome an opportunity to discuss this in more depth, HCS has recently announced that as much as possible they would like General Practitioner's to refer privately in order to lessen the burden on HCS. HCS is currently struggling with patient demand, and staff recruitment and retention, there is no resilience within the system and the public has lost some confidence with bad news health stories becoming main stream. The team at JWHH are all Jersey based and show long term commitment to the Island which we feel is important for personalisation and continuity of care, we have some concerns that patients are being under investigated before being considered for IVF.

Outsourcing or allowing patients to choose their provider whether that be private healthcare such as JWHH or ARU ensures patient need is met in a timely and efficient way. It also reduces the opportunity for a monopoly on services and therefore drives high standards. Both private and public services should work collaboratively and at a time where HCS is struggling to recruit and meet waiting lists this should be actively encouraged and comissioned.

JWHH partners with the Lister fertility clinic which has longstanding relationship and links with Jersey and the islands patients, if IVF funding were to follow the patient and the JWHH provide IVF for HCS patients it would be possible to have visiting UK specialists, ensuring we are help accountable and meeting continuous professional development needs, whilst providing patients with outstanding care.

Single consultant services, have been highly scrutinized, and recognised to not be a safe or sustainable means of practice. The Royal College of Physician's specifically noted this on recent review of the Rheumatology service.

13. What further steps should the Government of Jersey take, beyond this funding, to

support Islanders dealing with infertility?

Infertility law to support couples within the workplace, infertility is a disease affecting young working couples with responsibilities, could fertility appointments be given the same status as antenatal appointments and provision given for time out of work?

14. What are your thoughts on the Government's funding provision for women's health more generally?

Our thoughts on the government's funding provision of women's health more generally are many. We are disappointed that there is no funding for a UK style Women's health strategy, but would be keen to be involved in seeing what can be done to improve things. It may not be necessary for Jersey to have its own strategy and instead we could learn from the UK's.

There is a window of opportunity to develop the links between primary and secondary care, as plans for the new hospital develop. There are serious deficiencies in the current service such as the absence of a formal female incontinence service and no gynaecology ward. Having worked in a UK based "Women's Health Hub" it is quite clear commissioning of some services to off load hospital workload works very well. Women want to be seen in the community, at a suitable time, and for the majority of women's health issues a surgeon is not needed. To recruit 'good' consultants and supporting staff with such poor infrastructure and escalating unmet patient need is problematic, as demonstrated by the unacceptably high requirement to use locums and agency staff.

Ultimately, we would welcome an opportunity to talk face to face and discuss this further. We would also appreciate the chance to introduce Lister Fertility Clinic our off-island IVF providers, to discuss possible care provision

Kind Regards,

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