NHS
North Central London
Integrated Care Board

Development of NCL Fertility Policy – response to feedback received

1 Introduction

In North Central London there are currently five fertility policies in place – one for each borough. This is because, before the formation of North Central London Clinical Commissioning Group (NCL CCG), each CCG had its own policy and there are some variations between the five policies.

Work has been underway since 2021 to create a single policy for NCL that will provide consistency and greater alignment with The National Institute for Health and Care Excellence (NICE) guidance compared to existing policies. It increases the provision of specialist fertility treatments in the majority of boroughs, and, when approved and subsequently implemented, will provide a significant improvement in the standard of provision for the majority of NCL residents.

Significant engagement with local people and communities was undertaken in 2021 to develop a draft policy, with further engagement between 22 November 2021 and 13 February 2022 (12 weeks) to seek views from patients, residents, clinicians and voluntary and community groups before the policy was finalised.

A **feedback report** has been produced, summarising the key findings from this second phase of engagement. Having considered the feedback, the policy has been updated and finalised.

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Changes to the policy following feedback

There are a several areas of the policy that have changed following feedback from the community, including:

A. Extending storage for younger fertility preservation patients

The policy **now funds storage of cryopreserved eggs, embryos or sperm until at least the patient's 43rd birthday** and for a **minimum of ten years**. This upper age limit is consistent with the NCL Fertility Policy upper age limit criteria for assisted conception treatments for patients with fertility problems.

The draft policy stated fertility preservation patients would have frozen sperm, eggs and embryos stored for a maximum of ten years. Feedback noted younger patients may not be ready to start a family within ten years of having this procedure. The policy was changed so that younger patients have longer storage.

B. Excluding adopted children from the previous children criterion

Many people were in favour of the position of the draft policy which allowed treatment where one person in the couple (or an individual) does not have a living child.

However some people suggested this could be unfair to people who have adopted a child, especially where this is due to special circumstances (e.g. they have adopted the child of a family member who has died).

The policy has been amended to exclude adopted children from consideration allowing access to fertility services for those with adopted children.

C. Delay to funding of donor sperm/eggs

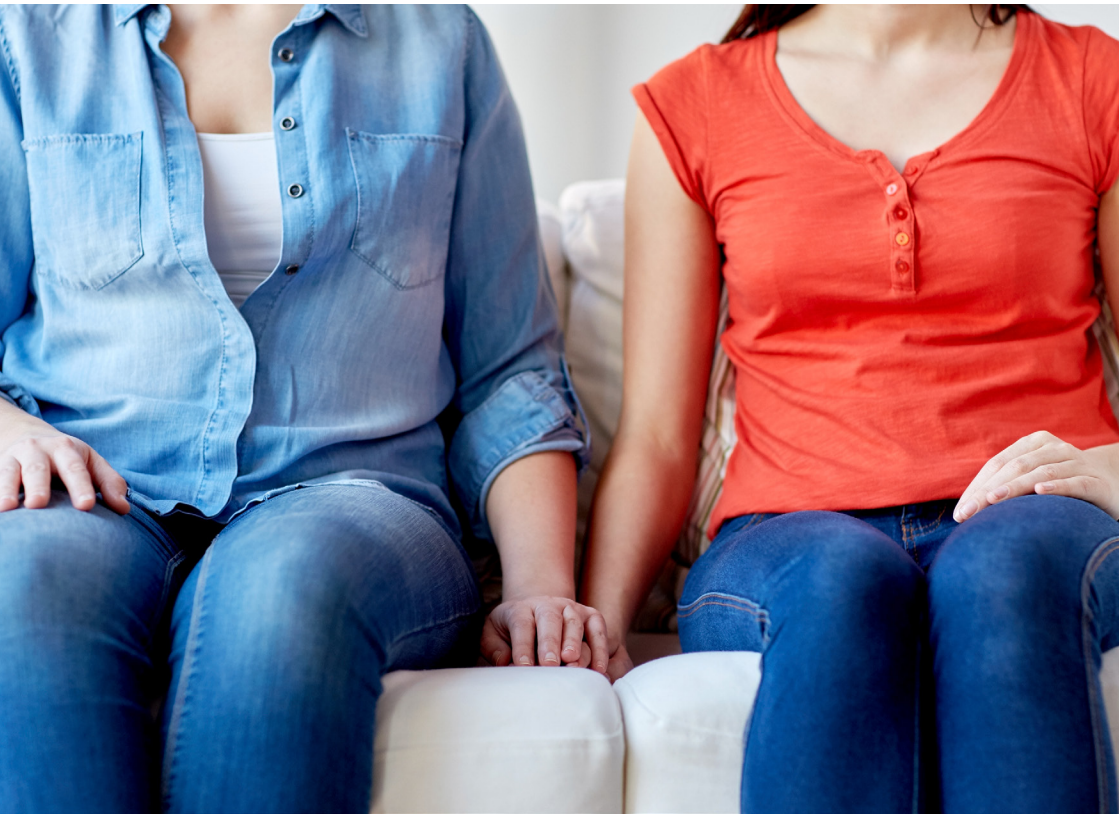
NCL **intends to fund donor eggs** for use in NHS funded assisted conception treatments (ACTs) **in the future**. Arrangements need to be put in place to resolve practical and logistical issues before this can happen.

The draft policy stated the CCG would fund the cost of ACT and the cost of donor sperm or eggs for eligible patients. Feedback received from local providers highlighted significant practical and logistical issues relating to CCG funding of donor sperm and eggs. Implementation of this part of the policy has therefore been delayed.

D. Improving the readability and inclusivity of the policy

The policy has been **reviewed to ensure it is as clear as possible**. Key actions have included: changing wording to better explain criteria, further explanation of technical terms and reducing the number of acronyms.

More **inclusive language** has been used, in response to feedback that suggested the draft policy was 'heterocentric' and 'non gender inclusive'.



E. Providing accessible versions of the policy

A leaflet is being developed aimed to support residents to understand the policy and what it means for them. A communications plan has been developed to raise awareness of the policy and support local people to understand how changes to the policy might affect residents.

The policy is a complex and technical document and feedback recognised the need for something aimed at residents.

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Key areas of the policy which have stayed the same

Some feedback received has not been acted on, for example to keep the policy in line with NICE guidelines, including:

Maintaining the age criteria for women or people trying to get pregnant

Feedback suggested; age limits could result in pressure for women and increase gender imbalances in society, some women may be focused on other aspects of their lives or are not in a relationship until their late 30s or early 40s and that some women aged over 40 are getting treatment in Europe, so why not in the UK.

NICE does not recommend NHS funded in vitro fertilisation (IVF) for women aged over 42 years because the success rates decrease as the age of the woman, or person trying to get pregnant, increases. National data shows that the same is true for other assisted conception treatments.

Maintaining BMI criteria for women or people trying to get pregnant

Feedback suggested that Body Mass Index (BMI) as a measure does not take account of muscle tone, overall health or the reason why the individual is obese. There is also cultural desirability in some communities for women to be larger and therefore losing weight may be difficult.

Having a BMI outside this range (19-30 kg/m^2 in terms of the policy) is likely to reduce the success of assisted conception treatments. NICE guidance suggests, and the full Human Fertilisation and Embryology Authority (HFEA) Commissioning Guide states, that women should have a BMI of 19-30 before commencing assisted reproduction. Local specialists also support the inclusion of the BMI criterion outlined in the policy.

Maintaining the ovarian reserve criterion

Some stakeholders stated that the ovarian reserve criterion should not apply to younger people, noting that NICE guidance only recommends ovarian reserve criterion apply to women aged 40-42 years. The issue of how to define the specific tests that would determine low ovarian reserve was also raised in some of the clinical feedback.

Although NICE only applies an ovarian reserve criterion to women aged 40-42, in general, lower ovarian reserve is associated with a decreased chance of a live birth. Funding more IVF cycles for people with a good ovarian reserve is likely to lead to more live births than funding fewer IVF cycles and removing the ovarian reserve criterion.

The wording of the criterion has been updated to make this clearer and more consistent for providers to apply.

Maintaining the previous IVF cycles criteria

Feedback received suggested that it was unfair that people who have previously paid for IVF cycles would have less or no access to NHS funded treatment. This was felt particularly unfair for those nearing the upper age criteria.

However the likelihood of a live birth decreases with the number of unsuccessful IVF cycles undertaken. The policy is in line with NICE recommendations which are based on evidence-based research.

Maintaining a requirement for same sex couples and single women to have undertaken six cycles of self-funded intra-uterine insemination (IUI) before they are eligible for NHS funded IUI

A large proportion of responses (including from a number of Healthwatch and voluntary organisations) supported reducing or removing the number of self-funded cycles of IUI (intra-uterine insemination) required for female same-sex couples, single women, and other couples trying to conceive using donor insemination, who do not have a diagnosed fertility problem prior to NHS treatment.

Feedback suggested that the draft policy does not allow equality of access to same sex couples as they would be financially disadvantaged by the requirement to pay for six IUI cycles. This requirement could lengthen the process and, for some individuals, could mean they pass the age cut off for NHS treatment. It could therefore be seen as discriminatory, as same sex couples and single people cannot conceive without fertility treatment. It was argued that this aspect of the draft policy was not in line with NICE guidelines.

The NICE CG156 full guideline on fertility states:

- 'For women in same-sex relationships, there should be some period of unsuccessful artificial insemination (AI) before they would be considered to be at risk of having an underlying problem and be eligible to be referred for assessment and possible treatment in the NHS'.

NICE recommends that same sex couples should have access to NHS funded assessment and treatment once they have undergone six unsuccessful cycles of artificial insemination. When NICE made this recommendation they were trying to determine what would be equivalent to heterosexual couples, who have to try to conceive for at least 12 months before NHS assessment and possible treatment. NICE considered the financial cost of AI to same sex couples when making their decision.

The policy requires this AI to be IUI at a fertility clinic, rather than AI at home, for the following reasons:

- In the UK it is not legal for patients to purchase donated sperm from a licensed sperm bank to use at home.
- Donated sperm used at licensed clinics must be checked for infections including HIV, hepatitis, syphilis and gonorrhoea. The donor's family medical history is also taken to identify any serious heritable diseases.
- Clinics undertaking IUI provide counselling to everyone involved in the donation process.
- Clinics will also check the semen to ensure the donor sperm is of good quality.
- IUI undertaken at a clinic will maximise efficacy (e.g. sperm will be placed in the uterus rather than the vagina and timing will be optimised).
- Having treatment at a clinic will mean that the donor is not a legal parent to any child born and the mother's partner (if she has one) will be recognised as the second legal parent.

We recognise that those who gave feedback and shared their views about this aspect of the policy will be disappointed with the decision for this criteria to remain as is.

Not routinely funding assisted conception treatments involving surrogates

Feedback recognised that, for some, surrogacy is the only option to have a biological child. Not funding assisted conception treatments (ACT) involving surrogacy would exclude gay male couples and some women who have uterine or cervical factor infertility from NHS treatment, which was felt by some to be discriminatory. Some people felt that at least some aspect of surrogacy should be funded by the NHS.

There is no national guidance on NHS funding of ACT involving surrogates. Other reasons ACT involving surrogates is not routinely funded are:

- Funding treatments using a surrogate may be unfair to people who cannot afford to pay the surrogate's expenses, which may be up to £20,000.
- There are a lot of legal issues surrounding surrogacy, for example surrogacy agreements are not legally enforceable.
- Ethical issues may arise during the course of a surrogacy arrangement including intended parents or the surrogate changing their minds or disagreeing whether a pregnancy should continue if complications arise.

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Next steps

NCL would like to thank local people and communities for giving up their time to respond and providing their personal experiences of accessing and receiving fertility services. Feedback has helped to inform the, now final, **policy**.

Where interventions are not routinely funded through the policy, an individual funding request (IFR) application may be submitted by the treating clinician for any situation where they believe the case is clinically exceptional or rare.

NCL Integrated Care Board (formerly NCL CCG) is committed to updating the policy, should there be any changes in national guidance in relation to fertility treatments.

We have understood the importance of raising awareness of what the new policy will mean for current and future individuals who may have need of fertility services. We are planning a programme of activity to raise awareness of the policy and to provide information in accessible ways to support people to access services.

To find out more, contact: nclicb.fertility@nhs.net

This leaflet describes our response to the feedback received during the engagement period of the policy development. If you would like this leaflet translated, email nclicb.fertility@nhs.net

تصف هذه النشرة ردنا على التعليقات المستلمة خلال فترة المشاركة في وضع السياسة. إذا كنت تريد ترجمة هذه النشرة، فيمكنك إرسال بريد إلكتروني إلى nclicb.fertility@nhs.net

নীতিটি তৈরি করার সময় আমরা যে প্রতিক্রিয়া পেয়েছি সে বিষয়ে আমাদের মতামত এই লিফলেটটি বর্ণনা করে। আপনি যদি এই লিফলেটটি অনুবাদ করাতে চান তাহলে nclicb.fertility@nhs.net **ইমেল করুন**

Niniejsza ulotka opisuje naszą odpowiedz na opinie otrzymane w okresie opracowywania polityki. Jeśli chcesz otrzymać tłumaczenie tej ulotki, napisz na adres: nclicb.fertility@nhs.net

Waraaqdaan xogtu waxay sharxaysaa jawaabta aan ka bixinay falcelintii dadku baxsheen intii lagu jiray mudada aruurinta fikradaha ku aadan samaynta xeerka. Haddii aad doonayso in waraaqdaan laguu turjumo, iimeel u dir nclicb.fertility@nhs.net

El presente folleto contiene nuestra respuesta a las opiniones recibidas durante el período de participación para la elaboración de la nueva política. Si desea que el folleto sea traducido a su idioma, envíe un correo electrónico a nclicb.fertility@nhs.net

Bu broşür, politika geliştirilmesinin katılım dönemi boyunca alınan geri bildirime yanıtımızı ortaya koymaktadır. Bu broşürün tercüme edilmesini isterseniz şu adrese e-posta gönderiniz: nclicb.fertility@nhs.net

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