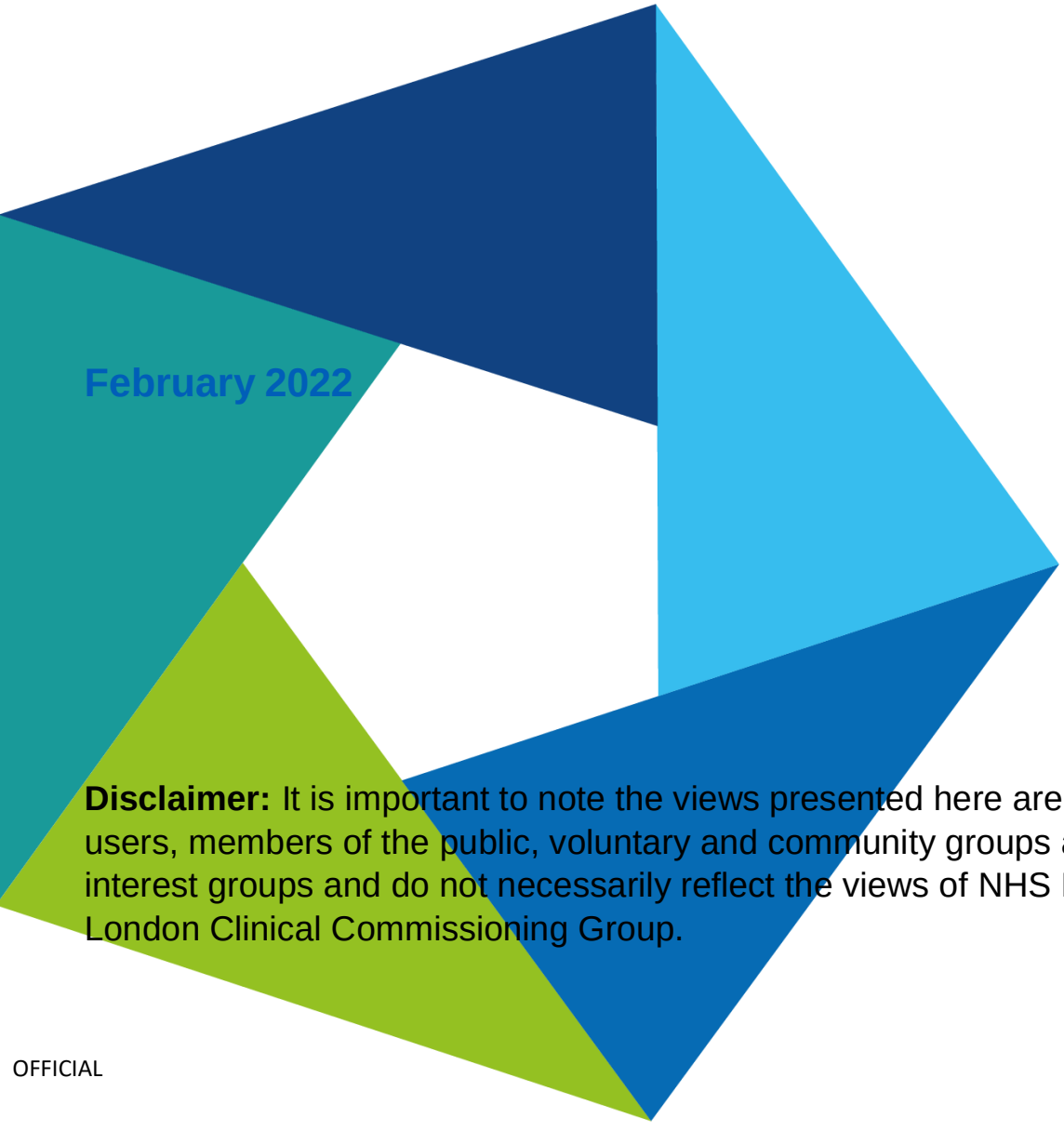
NHS
North Central London
Clinical Commissioning Group

NCL Fertility Policy Development:

Engagement Feedback report



February 2022

Disclaimer: It is important to note the views presented here are those of service users, members of the public, voluntary and community groups as well as special interest groups and do not necessarily reflect the views of NHS North Central London Clinical Commissioning Group.

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You may find in the report reference is made to medical/ physiological terms and we have attached a Glossary which we hope is helpful. The language has not been changed as it is part of the feedback received from respondents.

1. Executive summary

North Central London Clinical Commissioning Group (NCL CCG) was formed in April 2020, with the merger of the five North Central London CCGs: Barnet, Camden, Enfield, Haringey and Islington. Each borough had its own fertility policy and with the formation of a single clinical commissioning group, NCL CCG has been working to develop a new, single policy which will cover all five boroughs.

The first phase of this work was a review, during which we sought the views of patients, residents and clinicians and examined clinical evidence and national guidance. From this, a set of recommendations was produced to inform the development of a new policy. During the second phase of policy development, a draft single policy was produced. The draft policy sets out which fertility treatments and other services are funded by the NHS for residents across all five boroughs. It also sets out the eligibility criteria patients must meet to receive these fertility treatments.

We (NCL CCG) undertook engagement on the draft policy between 22 November 2021 and 13 February 2022 (12 weeks) to seek views from patients, residents, clinicians, voluntary and community groups, fertility groups and other audiences. This report provides an in-depth analysis of the qualitative and quantitative insights captured during the engagement.

Overall, our engagement identified good support for the draft policy, with respondents welcoming the proposal to increase provision of NHS funded treatment, standardise what is provided across the five boroughs, and bringing the policy more in line with NICE guidelines.

The engagement generated feedback on a wide range of issues and it should be noted that some of the feedback we received was polarised. This may be due to the important and sensitive nature of this topic, and influenced by the personal situations of those experiencing fertility issues or undergoing treatment.

This section of the report summarises the key findings of the engagement, with a summary of who we heard from during the engagement and the reach of different engagement activities. Later sections of this report provide detailed analysis on:

- Feedback received on the different aspects of the policy (including the eligibility criteria),
- Feedback on how readable the policy is and how awareness of the policy can be increased
- Comments raised by different audiences and population cohorts, highlighting similarities and differences where relevant.

The Fertility Policy Development team are currently considering the comments received during the engagement. Where appropriate, additional work will be undertaken to further research issues raised and we will discuss them with our internal stakeholders, such as the Clinical Reference Group, key consultants in the arena of fertility, and with our clinical colleagues on the Governing Body. We are also seeking legal advice on some matters to ensure that our Policy complies with our equality duty and with our legal duties generally.

The approval of the final policy will be made by the NCL CCG Strategy & Commissioning Committee (subject to timelines and any changes in governance should the transition to the NCL Integrated Care Board need to be considered). Additionally, we will also need to update our Equality Impact Assessment and our Quality Impact Assessments to align with the final policy.

According to current planning assumptions, we are expecting the final policy to be approved in late May 2022. We cannot yet confirm exact dates for the “go-live” of the new policy, but again, given current planning assumptions, we are expecting implementation to commence in summer 2022.

1.1 Key findings

Overall, there was a high level of **support for the policy** (68% of survey respondents and the majority of people who attended the public meetings (more than 80%)), with respondents seeing the draft policy as an improvement with recognition that its implementation would **increase provision**, **standardise** what is provided across the five boroughs and bring services offered more **in line with NICE guidelines**.

An extremely wide range of comments were provided through responses to the survey and in public meetings, across almost all aspects of the policy. Whilst the majority of responses received were in support of the draft policy, there were three areas that received the highest number of consistent comments, related to specific aspects of the draft policy:

- **Eligibility criteria should be reviewed** in the following areas: upper age limits of the woman, ovarian reserve and potentially removing criteria around previous IVF, BMI and previous children.
- It was strongly felt that **female same sex couples and single women should not have to self-fund intrauterine insemination (IUI) prior to** NHS treatment.
- Further consideration to providing assisted conception treatments for those seeking to use **surrogates**.

Although the engagement was primarily intended to seek views on the contents of the draft policy, we also captured feedback on how accessible the policy was and what the CCG could do moving forward to promote awareness and access to treatment. Common feedback themes related to these areas were:

- The **draft policy was felt to be readable**, but many requested an easy read/patient facing version be produced in addition to a patient leaflet. Some respondents also suggested podcasts that would ensure those less familiar with the terminology and process, and/or those who do not read/ write or speak English, can understand what they are entitled to and at what stage to begin seeking treatment.
- Comments around **language** use – including feedback from the LGBTQI+ community, some of whom felt that language in the policy was hetero-centric and should be reviewed.
- Understanding who is likely to be affected by the policy and **supporting raising awareness** of the policy - many recognised GPs as the first port of call for information and referral, and recommended training on the new policy. Using existing channels/forums will help in socialising policy, but there was recognition that more proactive methods will be needed, including “going to” where people are.
- **Personal experiences** shared showed **no two experiences of fertility treatment are the same** – with feedback received regarding confusion about what can be accessed and when, reports of long waits for treatment and for tests (with noted exacerbations due to the Covid pandemic), and difficult decisions that individuals and couples have to make about whether private treatment and more specialist forms of treatment are an option.
- **The significant impact of infertility and fertility treatment on mental health was highlighted**, and feedback welcomed the policy as an opportunity to more proactively signpost to support available.

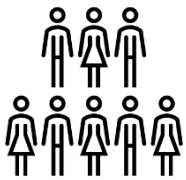
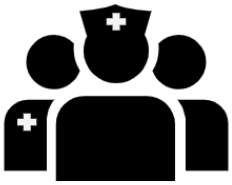
1.2 How did people engage?

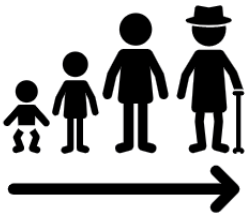
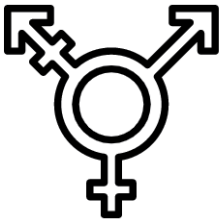
Table 1: Engagement response

	**439** responses, in total, to the engagement		**21** engagement meetings
	**108** responses to the online survey		**56** voluntary and third sector groups responded **142** contacted directly
	**2,258** webpage views with **1,988** documents downloaded		**80,507** **"impressions"** where content was displayed on residents/voluntary sector social media feeds

1.3 Who responded?

Table 2: Respondent profile where disclosed (includes the demographic details of people who attended public meetings and completed the fertility survey).

	**28%** of survey responses from current or former service users		**48%** of survey responses from members of the public
	**12%** of survey responses from NHS staff		**56%** of the public respondents were White British and **25%** were from Black and other minority ethnic groups

	**27%** of survey respondents were aged between 25-34 and **33%** between 35-44		**17%** of public respondents identified as Gay, Lesbian, Bisexual or other gender
	**50%** of survey respondents had a religion or belief		**70%** of public respondents were women, **22%** were male and **3%** were non binary / identified in another way.
	**13%** of survey respondents had a disability		

1.4 Where did responses come from?

The majority of responses (where borough location was disclosed) received from the survey and in public meetings were from people in the borough of Enfield (33%) followed by Camden (23%), Haringey (23%), Barnet (14%) and Islington (7%).

2 Engagement methodology

2.1 How the communications and engagement programme was designed

Our engagement approach was based on social research methodologies in order to ensure it was:

- Rigorous and systematic;
- Designed to develop rich insights and reflect views impartially;
- Facilitated to cover the key topics; and
- Delivered through a range of engagement mechanisms appropriate for different groups.

Learnings and insights generated through the engagement during the Review phase were used to inform the approach taken for the second period of engagement on the draft policy. This included helping us to develop a detailed picture of who we wanted to engage in this phase (see Table 3). The engagement window opened on 22 November 2021 and closed on 13 February 2022.

Special mention should be given to the CCG Community Members on the Fertility Policy Development Steering Group, NCL Community Member Readers Panel and local Healthwatch Groups who assisted in helping us finalise and adapt our communications and engagement approach.

Table 3: Stakeholder map

Group	Details
Individuals that participated in phase one of engagement (Review)	• Survey respondents • Participants who attended phase one engagement events, interviews and focus groups • People who registered to be kept up-to-date with the Fertility Policy Development
Service users and residents	• NCL Residents Health Panel • Local NHS Foundation Trust members • NCL CCG Community Members • Local and national fertility groups members • NCL GP Patient Participation Group Networks (PPGS) • Members of the public
Community, voluntary and charity sector organisations, resident associations	• Local Healthwatch organisations • Local patient representative groups and charities • Special interest groups
NHS secondary care partners and Fertility service providers (NCL)	• University College London Hospitals NHS Foundation Trust • Imperial College Healthcare NHS Trust • North Middlesex University Hospitals NHS Trust • Homerton University Hospital NHS Foundation Trust • Guy's and St Thomas' NHS Foundation Trust • Central and North West London NHS Foundation Trust • Whittington Health NHS Trust • Royal Free London NHS Foundation Trust
Primary care	• GP member practices (including GPs, practice nurses, practice managers and administrative staff) • Primary care networks (PCNs) (including clinical directors)

Local authorities	• Communications and engagement teams
Political stakeholders	• MPs • Council Leaders (HOSC, JHOSC Chairs and Cllr leads for Adults and Social Care across the five boroughs) • North Central London's Joint Health Overview and Scrutiny Committee (JHOSC), • Health Overview and Scrutiny Committees (HOSCs)
North Central London CCG	• Governing Body • Clinical leads • Executive Management Team • All other staff

Communications Approach

The communications approach focused on ensuring:

- Demonstrating how the final draft policy was developed, including clearly showing how engagement feedback from the first phase was used;
- The scope of the policy development phase was clearly outlined and stakeholders were informed about the policy development process;
- That messaging / information shared was consistent, accurate and timely throughout and materials were in plain English (with other languages and formats on request);
- All CCG communications channels were used to promote engagement activity, and that partner organisations were also utilised as far as possible;
- We made it easy for people to understand, and feedback their views on the proposed policy (e.g. providing a summary of key differences between legacy policies and the draft policy);
  and
- That the CCG responded quickly and accurately to all correspondence received through the engagement period.

Engagement Approach

The engagement approach focused on ensuring:

- Opportunities for stakeholders to contribute to the policy development were maximised through offering a range of methodologies and channels, and used existing links and forums, as well as establishing new links where necessary;
- The range of voices informing our policy development reflected the diversity of our communities, including those from seldom heard groups;
- We worked with partners, such as fertility groups and provider communications teams, to reach those affected by fertility issues and our service users (past and present);
- Views of key political (local JHOSC members, Councillors), scrutiny and primary care stakeholders were sought, reflecting our statutory duties and duties as a membership organisation;
- The CCG had effective processes in place to gather and analyse engagement responses to inform the policy development; and
- That our engagement also sought views on, when the final policy is agreed, how the CCG can support ensuring wide awareness and understanding of it across key audiences.

Fertility Policy Development (FPD) Steering Group

The membership of the Steering Group included two Community Members, one representative from Fertility Network UK and one resident (who has a role with the CCG on our Patient and Public Engagement Committee). The Community Members provided advice on our communications and engagement approach and advocated for residents and services users during Steering Group discussions, including reviewing engagement findings throughout the engagement window.

NCL Community Member Readers Panel

Six CCG Community Members (one from each of the five boroughs in NCL and our resident Community Member on the Steering Group), were invited to form a Readers Panel, assisting the CCG in testing the communication and engagement materials (including the survey). They also reviewed the draft policy for its' readability prior to the start of engagement. The Readers Panel will be involved in developing our plans to promote the final policy, once implemented, to ensure wide awareness and understanding of the policy across the diverse communities in NCL.

Meetings with local Healthwatch during the engagement period

We held regular meetings with local Healthwatch groups throughout the engagement period, to share emerging themes from the feedback and seek feedback on areas of focus / 'gaps' to tailor our engagement activity.

Core engagement activity

NCL CCG was committed to being flexible in how we heard from residents, service users and groups, and welcomed conversations as well as the opportunity to attend existing events and meetings to discuss the development of the draft policy. Written comments were welcomed and processed through a single document management system and a consistent analysis framework.

As a result of the ongoing COVID-19 pandemic, engagement activities were undertaken through a digital first approach, ensuring engagement was as accessible and safe as possible. To support in reducing digital exclusion, options were provided to ensure accessibility for those without access to/ knowledge of digital devices and technology.

The core engagement methods implemented by the CCG were:

Survey

- Online version hosted on our public and GP websites
- Shared with our key stakeholder database, which included Healthwatches, VCS groups, special interest groups, local authorities and local hospital patient/membership groups.
- Distributed to the North Central London Residents Panel – a group of nearly 1,000 local residents with an interest in health and care services
- Distributed via Nextdoor (online neighbourhood network) with impressions across North Central London residents timelines.
- Promoted via CCG public channels, notably social media, newsletters (to the wider NCL system and also our residents newsletter), news articles on our public-facing website and our intranet (recognising that our staff may wish to share their views).
- Information was shared by Provider organisations (not only those part of the North Central London health and care system, but also those out of area who provide fertility services to our population).

- Healthwatches, local VCS, local authorities and other key partners through the Development period.
- Shared with local general practice teams (both GPs and via Practice Managers and PPG Groups) across our boroughs via NCL CCG GP website and newsletter.

Public and service user-focused activity

- Seven open-access online events were held for members of the public. These events were spread throughout the engagement period and were run at different times of the day, with one held at the weekend in order to allow the greatest accessibility for attendees with differing responsibilities.
- A focus group supported and chaired by a representative from Fertility Network UK (FNUK) with residents who had lived experience attending as well as representatives from the Donor Conception Network and CHANA (Leading fertility support organisation for the Jewish community).
- Attending local LGBTQI+ community meetings.
- Attended meetings with PPG representatives and promoted opportunities to get involved.
- Hosting a public meeting in collaboration with an NCL Community Member, which welcomed people from local ethnic minority communities whose country of origin was not the UK.
- Outreach via fertility group social media channels (e.g. FNUK and The LGBT Mummies Tribe), including a pre-recorded YouTube Podcast).
- A pre-recorded question and answer session with the Fertility Policy Development Clinical Responsible Officer and Programme Director, which were shared on the CCG's YouTube channel and via Instagram, Facebook, and Twitter.

Wider stakeholder-focused activity

- Scheduled meetings with local Healthwatch groups to discuss engagement activity and feedback received.
- Meetings with local organisations, including online groups, discussion sessions with groups Attending/presenting at meetings organised by others, such as Haringey LGBTQI+ Network, Camden Parents Forum, Enfield Saheli, and local community group network meetings.
- Information shared with our communications counterparts in local authorities and Trusts
- Information shared and discussed with North Central London Joint Health Overview Scrutiny Committee and North Central London Clinical Advisory Group (CAG).
- Information shared with NHS provider – Chief Officers, Medical Directors, Head of Fertility Units and Fertility Clinical and Non-Clinical staff.

2.2 How was the engagement period promoted?

A range of steps were taken to promote the engagement period, focused on directing people to the online survey or to attending events as the main way to give structured feedback.

- Website – The engagement website[1] hosted key materials, available in a number of formats, including:
  - Patient leaflet
  - Easy read patient leaflet (including an easy read version of the survey)
  - Link to the online survey

[1] 1. About the new draft policy - North Central London CCG

- Key supporting documents including; the draft NCL policy, current individual borough policies, equalities impact assessment and frequently asked questions

During the engagement period, the engagement website and hosted materials had over 2,258 page views and 1,988 documents downloaded. See below for a breakdown of the number of times each document has been download.

Document downloaded	Number of occasions
Draft Fertility Policy	89
Draft Fertility Policy Equality Impact Assessment	74
Barnet Fertility Policy	270
Camden Fertility Policy	355
Enfield Fertility Policy	251
Haringey Fertility Policy	264
Islington Fertility Policy	234
Recommendations report	70
Stage 1 Engagement report	68
Stage 2 Communication and Engagement strategy	58
Fertility Policy Development Patient Leaflet	64
Fertility Policy Development Slides	74
Easyread Patient Leaflet	54
Easyread Questionnaire	63

- Social media posts – on CCG Twitter, Youtube, Instagram and Facebook.
- Mailing databases of voluntary and community organisations – these were reviewed and refreshed following stage 1 of the policy development and contacts were sent information about the engagement exercise to share with staff, service users, local residents, voluntary and community groups.
- Partner channels – content was provided for statutory and voluntary sector partners.
- Engagement with local/key community groups – Mailings, emails and phone calls proactively engaged more than 140 community groups or organisations to make them aware of the engagement exercise and help promote it within their networks. This included regular communications and materials to support promotion of the engagement exercise through their channels, e.g. newsletters, mailing lists, social media.
- Presentations at local/ key community groups – invited to make them aware of the engagement exercise and help them to promote it within their organisations and to their service users and members.
- Information was shared via the monthly NCL Residents' Newsletter and monthly NCL System Updates

Partners and voluntary and community organisations were encouraged to retweet/ share posts made by NCL CCG.

2.3 Adapting our approach during the engagement period

The Fertility Policy Development Working Group reviewed the engagement activity weekly, to review emerging themes and to consider adaptations to our engagement plan to ensure we heard from diverse communities and stakeholder audiences.

As part of this, we regularly met with local Healthwatch groups during the engagement window to share emerging themes from the feedback and seek feedback on areas of focus / 'gaps' to tailor our engagement activity focus.

We also held regular meetings with the NCL CCG Community Member Readers Panel who assisted us in promoting the development of the single draft policy and the ways that service users and the public can get involved.

Some examples below show the ways we adapted from our discussions with Healthwatch groups and the Readers Panel:

- Healthwatch – messages changing from "fertility" to "ways to get pregnant" and introducing us to local LGBTQI+ leaders where we were unsuccessful initially.
- Readers Panel – as a result of discussions we developed posters and screensavers developed for display in general practice, acute and community patient settings (with QR codes) to improve our reach to current service users.

With local Healthwatch Groups and the Readers Panel we sought views from as many people and groups as possible and our methodology was rigorously designed to support this aim. Proactive communications and engagement activities were undertaken throughout the engagement window to promote awareness of the draft policy, including social media content across a number of channels, detailed information on our website, with an online questionnaire (also available as a hard copy (and easy read) on request), articles featured in our stakeholder and residents newsletters.

A range of approaches were taken to reach out to groups and individuals from different ethnic backgrounds and communities across our five boroughs. It should be noted that the engagement took place during the COVID-19 pandemic, which restricted engagement interactions to online and telephone methods. This regrettably resulted in moving from a public meeting that was planned to be held in person to be transferred to an online meeting. It is important to note that we received no negative feedback for taking this decision.

Wherever possible mitigations were put in place to enable and encourage people to take part; for example, by working with VCS groups to reach ethnic minority communities whose first languages are not English, and by providing interpreting support (Arabic & Somali) at online events.

3 Approach to analysis

This report includes responses from all feedback methods, including the online survey, online public meetings, social media, and written correspondence (via email). The executive summary gives an overview of the most frequently heard themes from across all feedback methods and audiences. More detailed commentary can be found in sections 5-9. Where appropriate, differential findings have been drawn out when comparing feedback from different respondent groups.

Thematic analysis was undertaken on qualitative responses from all feedback methods, to understand the breadth of feedback and consensus of opinions, where present.

Unless expressly stated, the themes within this report represent a majority view; in other words, the themes which were most commonly expressed. Due to the nature of fertility services, many individual comments were received about specific circumstances which meant there were few topics on which there was a consensus. A summary of the key themes raised, alongside their frequency, can be found in Appendix 4.

Some comments received related to personal experiences. These can be found in section 9 of the report.

It is important to note the views presented here are those of service users, members of the public, voluntary and community groups as well as special interest groups and do not necessarily reflect the views of NHS North Central London Clinical Commissioning Group.

Points to note regarding data:

- Some respondents may have fed back on the engagement exercise through more than one method, for example they may have completed the online survey and participated in an online public meeting, giving mirrored responses. This may mean that the number of responses received to the engagement exercise may be different from the number of people who participated.
- Not all survey respondents completed every question.
- Not all survey respondents or event attendees completed demographic information.
- Feedback presented is from the perspective of the respondent**. Some comments received suggest that there may be misinterpretation of what is contained within the policy, therefore highlighting areas to clarify when finalising the policy.**
- A small number of survey responses were incomplete/incomprehensible and have been left out of the analysis.
- When seeking to understand how views from specific groups may differ from others, we have used demographic data provided to us by respondents. For the purposes of this report, when looking to understand experiences of those from Black and other minority communities, we have included data from Black, Asian, Mixed and Other ethnic categories.

4 Feedback on the draft policy

4.1 Support for the policy

4.1.1 Summary of feedback

- The majority of all respondents (including 68% of survey respondents) expressed **support or strong support of the draft policy** and welcomed an increase in provision across the boroughs.
- The majority of feedback from those **not supportive** was around provision of assisted conception treatments for **female same sex couples**, with a call for access to be equivalent to heterosexual couples.
- There was feedback from some respondents that the policy seemed to **leave out/underserve certain communities** and people with some health conditions.
- There were also questions around the **implementation** of the policy.

Table 4: Overall support for services provided

Area	Percentage of respondents*
I strongly support/ support the draft policy	**68%**
I do not/ strongly do not support the draft policy	**26%**
Not able to say	**5%**
No view	**1%**

*To the survey

When compared with other respondent groups (within the survey):

- **Current or recent service users** were more supportive
- **Members of the public** were slightly less supportive
- **Healthcare staff who responded (Inc. general practice, CCG and clinical staff who provided fertility support** were more supportive
- **Voluntary organisations from the LGBTQI+ communities** were significantly less supportive, however written responses and responses received during public meetings groups suggest there is support for the policy from voluntary organisations
- **Those who identified as black or mixed ethnicities** were slightly more supportive when compared with those from white backgrounds
- **Those aged 16-45** were more supportive of the policy than those over 45
- There was no difference in support levels amongst those from **different religions**

4.1.2 Feedback on support/non-support for the policy

Those supportive of the draft policy believed it increased provision across the boroughs, and reduced inequalities in the treatments offered - reducing the "postcode lottery". It was also hoped that it would support a reduction in waiting times. Many felt the draft was in line with NICE guidance, leading to a fair and reasonable policy. One respondent stated:

"*This policy change is long overdue and I am so pleased with all that is being considered. I really do hope that this report comes in to effect…..Thank you, thank you!*"

Another commented:

"Makes a lot of sense making the policy more consistent across the areas, and am grateful for the increase in fertility service provision we'd get in barnet as a result. We currently have already used our 1 fresh ivf cycle in Barnet, so would be great to have access to two more funded cycles, as our current private cycles have been incredibly expensive".

Another participant said:

"*There should not be disparity between treatments and where you live. This policy equalised and deals with the current disparity".*

Other participants said:

"*It's great to see additional support for lgbt+ people with access to funding after 6 rounds, it is still wholly discriminatory & disproportionately denies access to lgbt+ people unless they pay for 6 rounds (up to £24k whereby heterosexual can gain access after inter course and trying for a baby for 2 years). Heterosexuals do not have to pay to do this whereas for many lgbt* people £24k or even much less is not financially viable & unattainable. Also within 6 rounds of iui at an average of 10-20% success rate most people will fall pregnant in that time so wouldn't get access to funding anyway.*

"If you want to ensure it is not discriminatory & provides equity and equality for all you need to provide access for all or another idea is to means test it dependent on household income for example."

Many specifically agreed with the provision of certain services, including the increase in available IVF cycles offered on the NHS, being able to have fertility treatment using NHS funded donor sperm and eggs, and funding of IUI for female same sex couples and single women (where an initial 6 cycles of self-funded IUI had been unsuccessful).

Some of those surveyed felt that the offer for female same sex couples was discriminatory, in particular those identifying from the LGBTQI+ community, due to the requirement for those who do not have a diagnosed fertility problem to self-fund six rounds of IUI before being able to access NHS treatment. It was felt this was not consistent with NICE guidance which specifies artificial insemination should be tried prior to NHS treatment (not specifically IUI). Questions were raised over why this group should be financially disadvantaged by meeting these costs themselves when this is not a requirement for heterosexual couples. Additionally, clarity was asked for around the criteria used to show that heterosexual couples have tried for two years.

In terms of the language used within the document, it was felt this could be more sensitive, in particular to the LGBTQI+ community and people living with HIV. Some terms and phraseology were felt to be heterocentric and (in relation to people with HIV) further stigmatising.

The duration which people with unexplained infertility were required to try to conceive were felt, by some, to need a review. The two year wait of naturally trying to conceive (at any age) for patients who do not have a confirmed explanation for their infertility was felt to be too long for older patients.

A small number of respondents were not supportive of the policy as they felt fertility services should not be provided on the NHS at all.

4.1.3 Comments on, and suggested changes to, the policy

Feedback on the policy fell into three broad categories; conditions or communities it was felt the policy missed or underserved, points of clarification and the impact of implementing the policy.

Communities or conditions missed or underserved

Some respondents felt the draft policy does not offer equality of access for female same sex couples and single women compared to heterosexual couples (due to the requirement to initially self-fund up to 6 cycles of IUI). The offer for women presenting with a transgender male partner was also felt to be unclear, needing to be more inclusive of the rights of transgender individuals.

One respondent suggested there could be a separate policy for female same sex couples and single women, which also encompassed the safe procurement of donor sperm.

Some respondents highlighted specific conditions or circumstances they felt had been overlooked, including; those with endometriosis whose ovarian reserve would not meet criteria, women for whom there is both vaginismus and male fertility issues and those with polycystic ovary syndrome.

Some people also felt that the policy did not cover the situation where a baby is lost (through miscarriage or stillbirth) following assisted conception treatment.

A smaller amount of feedback highlighted concern in relation to IUI using partner sperm, specifically relating to people who are unable to, or would find it very difficult to, have vaginal intercourse because they have a physical disability. It was suggested that the draft policy directly discriminates against people with the protected characteristic of disability because, unless they have a diagnosed fertility problem, these patients are required to initially self-fund IUI.

Points of clarification

From the feedback received from respondents about the policy was questions around specific circumstances or clarifications around eligibility. This included:

- **Immigration surcharge** - There were a number of questions/scenarios highlighted, including: if an individual in a couple is paying a surcharge are neither eligible? It was felt this could be discriminatory to the individual who is eligible. Questions were also raised over whether couples would be able to mix care if one is illegible and one is eligible (i.e. could half of the treatment be funded if half is paid or if the female treatment is more costly does the ineligible male pay only for his proportion?).
- **Cancelled cycles** – requesting clearer definition on this aspect, including what happens if egg collection is completed but there is no embryo transfer. Respondents suggested that the policy include a clause for when that occurs.
- **Home insemination** – understanding if this is included under the term of 'artificial insemination' (part of NICE recommendations on IUI) and if not, setting out the rationale for why not.
- **Exploratory measures** – clarifying what infertility diagnostic tests and procedures are available on the NHS to eliminate or diagnose issues, prior to fertility treatment. Some people also asked whether this is the same for same for female same sex female couples, which may then lead to them becoming eligible for fertility treatment.
- **Embryo transfers** – Some questions requested further clarity on how many cycles are funded and how this relates to the number of embryo transfers As an example, if somebody had two embryos transferred at the same time would that count as one or two cycles. If a

women goes through a stimulated cycle and produces multiples embryos, confirming whether she needs to pay for further transfers if she has more cycles.
- **Quality of embryos –** recommendation to include definitions of embryo quality. One respondent asked if a "low quality" embryo is used this would count as one transfer.
- **Use of paid donor recruitment agencies** – asking for confirmation that recipients who use these services are not excluded from the policy.
- **Specialist clinical recommendations** – where clinicians have recommended a treatment not explicitly covered in policy, what mechanisms are in place to apply for funding.

Impact of implementing the new policy

From the feedback received questions were asked about how the policy would be implemented, and potential impact on NHS services, and included requests for:

- Confirmation of the timeline for implementing this new policy.
- Confirmation whether people already on a treatment pathway would not become ineligible under the new policy, when implemented
- Confirmation whether current patients will benefit from the new policy/ clarification how the new policy would be applied to patients already on a treatment pathway
- Clarifying whether if someone has had some NHS treatment, and since gone privately, can access further NHS treatment under the new policy.
- Clarifying why there is not a national policy or a London policy.
- Need to streamline testing in primary care to support with swift referral onto this pathway.
- Confirmation that existing maternity service capacity would not be impacted.

4.2 Specific concerns and suggested actions to take

In the survey and in public meetings, respondents were asked about their concerns with the policy and any specific actions the CCG should take before the policy is finalised.

4.2.1 Concerns

The majority of concerns were around access to the policy for specific population groups.

Gender and sexuality based differences - it was felt by some people that the policy was discriminatory to those in female same sex couples including those who have transitioned gender. The draft policy includes a requirement for female same sex couples without a diagnosed fertility problem to self-fund some treatment before being able to access NHS services. There was recognition that gay male couples find it difficult to have a biological child and some people felt that this was not addressed in the policy. It was noted that, in general, the perception is that testing for female infertility is less supported and funded than male fertility issues.

Single women and couples with psychosexual issues – again it was felt these groups were disadvantaged by the policy in the same way as same sex couples and those with physical disabilities.

Ethnicity based differences – using BMI as a criteria was felt to negatively affect those from certain ethnic backgrounds.

Location of treatment – there were concerns around patient choice and whether it will be possible for individuals to choose where they receive treatment not associated to where they are registered with their GP.

Clarity on eligibility – some felt there was a lack of clarity on which "fertility problems" are eligible for NHS funding.

Funding – with an increase in access to some fertility treatments and services, there were concerns around funding being available to implement the policy. One respondent noted that funding is inequitable across age groups due to age eligibility criteria. It was also felt the funding of fertility services needed to be carefully balanced with spending on other more critical services.

Encouraging access – concerns were particularly raised by Healthwatch organisations and the NCL Readers Panel on encouraging awareness amongst communities who may not traditionally access services, for example black and minority ethnic groups and the LGBTQI+ community.

4.2.2 Suggested actions for the CCG

As part of our engagement, we asked whether there were any actions that respondents would recommend the CCG took to address any concerns they had regarding the draft policy. This sections outlines the main feedback provided in relation to this.

A significant amount of the feedback received was seeking clarity on specific parts of the policy, as well as suggesting changes to the policy and criteria. These are outlined in other sections of this report.

Feedback regarding other proposed actions fell into three main themes - provision of additional information; service improvement and performance management; and policy review.

Provision of additional information

- Creating a public facing companion document to the full policy that gives context to what the journey might be like, timescales, what support is available and what other investigations that people need to go through before being referred for treatment.
- Proactively signposting to support (e.g. counselling) and other services, whether the NHS will be funding their treatment or not.
- Creating an online eligibility questionnaire that can be embedded on websites to help prospective patients easily understand whether they are eligible for treatment (and the type of treatment).

Service improvement and performance management

- Offer intensive training to all health care professionals on the new policy and pathway (including HIV guidance).
- Monitor uptake of fertility services across NCL to ensure that this service is being equitably accessed by protected characteristics and practice.
- Monitor where referrals are coming from – there was recognition that referral rates would vary naturally but areas experiencing significantly lower referral rates may helpfully flag areas where further education, training and community engagement may be beneficial.
- Monitor success rates and performance manage individual Trusts, offering contracts accordingly.

- Ongoing engagement with local communities (including HIV support organisations) to understand difficulties - particularly those accessing services at a lower rate, such as: ethnic minority backgrounds and the LGBTQI+ community.

Policy review

- Take account of the local population needs and mindsets and adapt treatments and services accordingly.
- Adjust the policy when new evidence becomes available.

5. Feedback on service provision in the draft fertility policy

Table 5: Overall support for proposed service provision under the draft policy

Area	Survey responses
IVF, with or without ICSI (intracytoplasmic sperm injection)	**Supportive of the proposal** (65% strongly agreed/agreed) 7% strongly disagree/disagree. 15% neither agreed/disagreed and 13% had no view/preferred not to say.
IUI using partner sperm (intrauterine insemination)	**Supportive of the proposal** (61% strongly agreed/agreed) 7% strongly disagree/disagree. 15% neither agreed/disagreed and 17% had no view/preferred not to say.
IUI and IVF using donor sperm	**Supportive of the proposal** (51% strongly agreed/agreed) 13% strongly disagree/disagree. 20% neither agreed/disagreed and 16% had no view/preferred not to say.
IVF using donor eggs	**Supportive of the proposal** (58% strongly agreed/agreed) 10% strongly disagree/disagree. 19% neither agreed/disagreed and 12% had no view/preferred not to say.
Surgical sperm retrieval	**Supportive of the proposal** (52% strongly agreed/agreed) 6% strongly disagree/disagree. 23% neither agreed/disagreed and 19% had no view/preferred not to say.
Assisted conception treatments involving surrogates	**Mixed Views** (42% strongly agreed/ agreed) 23% strongly disagree/disagree. 23% neither agreed/disagreed and 12% had no view/preferred not to say.
Sperm washing	**Supportive of the proposal** (54% strongly agreed/agreed) 6% strongly disagree/disagree. 23% neither agreed/disagreed and 17% had no view/preferred not to say.
Cryopreservation of gametes for fertility preservation (freezing of eggs/ embryos/ sperm)	**Supportive of the proposal** (58% strongly agreed/agreed) 10% strongly disagree/disagree. 19% neither agreed/disagreed and 12% had no view/preferred not to say.

Comments on the service provision

Some comments from the respondents are given below. One respondent stated:

“It looks good. I am pleased we are offering donor eggs for those with conditions like turners that want to be parents but don't want to pass on their conditions”

Another respondent commented:

"Female same sex couples should not have to fund six cycles of IUI before they are eligible, it should be the same like heterosexual couples. Same sex couples should be eligible for surrogacy treatments in order to be given an equal opportunity as heterosexual couples to become parents."

Other comments stated:

"Female same-sex couples should have funding for IUI from the start. In 2021 this feels outdated and discriminative towards same sex couples."

"Great that up to 3 rounds of ivf required if needed - i think this is a big change aware that plenty in the press about iui for lgbt+ couples - i think you should fit with national picture, but be clear that you would change this immediately should the national picture/legal picture be made clearer. Understand that you will now pay for donor eggs/sperm - do you think it will be easy to source this - what happens if you can't? Timeframes for freezing good to clarify - whose responsibility is it to inform if go past nhs eligibility in future? what happens to those stored materials/embryos"?

5.1.1 IVF, with or without ICSI

The majority of people were supportive of the level of provision for IVF, recognising that for most residents in NCL it will result in an increased level of provision and is standardised across all boroughs. Where comments were made about the level of IVF provision, a number of responses suggested that three full cycles should be provided as recognised and defined by NICE (i.e. no limit on the number of embryo transfers), with funding for treatment using both frozen and fresh eggs. One organisation recognised the policy around IVF improves the offer in their particular borough.

Some feedback sought clarification as to why natural IVF cycles were not funded. Also, why is IVF not offered for those who have physical disabilities or psychosexual causes for their infertility or fertility issues, in recognition that IUI may not be clinically appropriate (or tolerated) for all in this group. One respondent asked for a clearer explanation of a cycle entitlement – feeling it gives the perception that what is offered is three full cycles when it appears to be partial cycles.

5.1.2 IVF using donor eggs and /or donor sperm

Several respondents felt that the proposed funding of donor eggs on the NHS was positive and would make treatments more accessible to all, especially those who may have genetic conditions they do not want to pass on. However, it was felt that more clarity is needed around the policy for using donor eggs with IVF. One respondent questioned what quality control there would be to ensure donor eggs had no mitochondrial defects.

Comments suggested donor sperm should be funded in all treatment scenarios. One respondent felt frozen donor eggs should be used.

One respondent questioned how the policy supports provision for recipients who wish to use stored donor eggs that are only available in a private unit, without a contract with providers of assisted conception treatments. This is particularly pertinent for ethnic minorities where they may have no reasonable chance of finding a suitable donor.

One clinician commented that not all fertility service providers in NCL are able to offer assisted conception treatments with donor gametes.

In order to be eligible for fertility treatment, one respondent felt there should be greater checks in place for those seeking to access services. One respondent felt it was important that donor sperm quality checks were in place and another that potential mothers should agree to discontinue use of any recreational drugs or alcohol during pregnancy.

5.1.3 Intrauterine Insemination (IUI) using partner sperm or donor sperm

Feedback from some respondents indicated that there was some confusion about the number of IUI cycles that the NHS will fund and at what point in the process.

It was suggested that offering IUI as the first treatment option for all groups, prior to IVF, may be more cost effective and therefore more individuals to access NHS funded treatment overall. Some suggested offering six IUI cycles before moving onto IVF. One respondent felt that IUI needed to be stimulated for it to work, which they felt was not currently addressed within the policy. There was also the suggestion that there is a tendency to promote IVF over IUI, when some people consider that success rates are relatively similar. Some respondents noted that IUI is less intrusive and less risky, which may be particularly attractive to some individuals.

A small number of respondents suggested that IUI should be routinely funded for people with unexplained infertility, mild endometriosis or mild male factor infertility but not for severe male factor infertility or bilateral tubal blockage. There was also a question as to why women who require ovulation induction can't have IUI-D (to note: IUI-D is IUI using donor sperm).

For female same sex couples, a large proportion of responses (including from a number of Healthwatch and voluntary organisations) supported reducing/removing the number of privately funded cycles of IUI required for female same-sex couples or single women who do not have a diagnosed fertility problem prior to NHS treatment. It was felt that:

- by making sexual orientation the determining factor in whether treatment could or could not be accessed this aspect of the draft policy was discriminatory;
- that this aspect of the draft policy was not in line with NICE guidelines as NICE only specify artificial insemination, not IUI specifically;
- That this requirement could lengthen the process and, for some individuals, could mean they pass the age cut off for NHS treatment

A small number of respondents suggested the system may be fairer if a means-tested process is introduced, to ensure equality for all individuals wanting to access fertility treatment. One respondent advocated for aligning with the national approach to female same sex provision, but being clear that the policy would change immediately should the national picture/legal picture be made clearer.

It was felt that couples should not be expected to self-fund IUI with donor sperm and that donor sperm should be funded. One respondent called for greater quality control of donated sperm, including an upper age limit.

In terms of IUI with partner sperm one respondent questioned why heterosexual couples, who cannot have vaginal intercourse for medical reasons, have to pay for private IUI first.

5.1.4 Assisted conception treatments involving surrogates

Some feedback suggested that provision should be made for those couples or individuals where surrogacy may be their only opportunity to have a biological child. Several respondents indicated their disappointment at the lack of funding for assisted conception treatments involving surrogates.

One respondent felt there should be consideration of young cancer patients being funded the embryo creation and transfer costs to a surrogate as part of NHS treatment. It was also felt this should extend to fresh as well as frozen donor eggs.

It was suggested that, even if the full treatment involving a surrogate could not be funded, a proportion should be. One respondent raised issues with the policy for those who have had a hysterectomy for uterine cancer. They noted that the policy provided for fertility preservation, but would not fund surrogacy which would be required if a biological child was wanted.

Some people felt that male same sex couples should be eligible for surrogacy treatments in order to be given as equal an opportunity as heterosexual couples to become parents. It was also felt that there could be better quality at home insemination for same sex couples, such as advice, fertility drugs, and funded access to sperm if needed.

One respondent noted that intracervical insemination (ICI) is not recommended by NICE and suggested the reference within the policy is removed.

5.1.5 Sperm washing

Some people noted that due to improvements in treatment, a person successfully adhering to HIV medication treatments is very unlikely to pass on the virus to either their partner or a baby via sexual intercourse. They recommended that the wording in the policy be reviewed to update it to include the latest information on viral loads.

Some felt that sperm washing has limited evidence in people living with HIV and promoting the use of this technique could be seen as further stigmatising this community.

One respondent felt men should be compliant with anti-retroviral therapy before being considered for sperm washing. A clinician commented that, sometimes, couples would prefer sperm washing for psychological reasons due to fear of transmission, even if the man is on effective treatment.

After sperm washing, one respondent noted that couples have to choose between six cycles of IUI or IVF. Clarification is needed as to why, in these circumstances, funding is less than for those using donor sperm.

One respondent noted that there was inequity in access to this treatment for gay men, and this should be addressed.

5.1.6 Cryopreservation of gametes for fertility preservation

There were mixed views as to whether provision of this service was positive or not. Some people felt cryopreservation is costly and wasteful, citing several academic sources as the basis for their comments. Whereas, some felt the provision of these services were helpful and should be expanded more widely. Respondents suggested that clarity is needed on whose responsibility is it to inform individuals if they are no longer eligible for NHS treatment in future and what happens to those stored materials/embryos after that time.

Several respondents felt there needed to be clarification around the number of years that the NHS would fund freezing of eggs, sperm or embryos. Feedback suggested that the policy reflect that the NHS had recently increased the storage limit for eggs, embryos and sperm to 55 years duration.

Respondents recommended that greater education and support is needed for couples with a cancer diagnosis/undergoing cancer treatment. In particular, it was suggested that raising awareness of the policy and the provision of cryopreservation of gametes with young people experiencing cancer treatment that might affect their future fertility was vital.

One clinician suggested including people who are undergoing a surgical condition that would lead to infertility in the scope of these interventions. For example enabling those experiencing the following conditions to have access: significant symptomatic ovarian endometriosis needing ovarian surgery, or recurrent ovarian endometriosis/ cyst that can decrease the ovarian reserve drastically.

Some feedback sought clarification on individual circumstances such as; recommending mixed care for those who freeze eggs at a young age and then need fertility support and suggesting that, for those without a uterus, there is funding for ovarian stimulation and cryopreservation.

One comment discussed cryopreservation of gametes for gender reassignment. It was felt that this isn't a medically necessary treatment and someone undergoing gender affirming hormone treatment is able to delay in order to undergo fertility preservation.

One respondent felt all women should be funded to cryopreserve embryos so that they can be used in subsequent private cycles if they want another child.

5.1.7 Suggested changes to services to be provided

From the feedback received the suggested changes to the service provision is as follows:

- Provide up to six cycles of stimulated IUI first, before moving to three full cycles of IVF.
- Fund stimulated IUI routinely for people with unexplained infertility, mild endometriosis or mild male factor infertility except where there is very severe male fertility problems or there is bilateral tubal blockage.
- Clarify the policy regarding NHS funded treatment using IVF donor eggs.
- Reconsider funding for assisted conception treatments involving a surrogate.
- Reconsider the policy to ensure that access for female same sex couples and single women is equal to heterosexual couples.
- Consider more routine funding of investigations for male fertility issues and ovarian reserve functioning.
- Enable ovarian reserve function testing in primary care, as early as possible, to enable women to make an informed choice.
- Increase the number of embryo transfers for women aged 40-42. Limiting this to two in the current draft of the policy may lead to women who cannot afford to fund subsequent embryo transfers 'choosing' to transfer multiple embryos at once which will increase their risk of a multiple pregnancies.

6 Feedback on eligibility criteria in the draft fertility policy

6.1 Summary of feedback

Overall, there was good support for the majority of eligibility criteria included in the draft policy. However, this did vary, with differences in the levels of support for the criteria, when reflecting on responses to the quantitative and qualitative questions. Quantitative responses (see table 6) were more supportive of some criteria than qualitative responses.

Table 6: Overall support for the eligibility criteria

Criteria	Majority of respondents*
Age of the woman	**Supported the criteria** (61% strongly agreed/agreed) 20% strongly disagreed/disagreed. 10% neither agreed/disagreed and 8% had no view or preferred not to say.
Previous IVF cycles	**Supported the criteria** (56**%** strongly agreed/agreed) 19% strongly disagreed/disagreed. 16% neither agreed/disagreed and 9% had no view or preferred not to say.
Body mass index	**Supported the criteria** (53**%** strongly agreed/agreed) 26% strongly disagreed/disagreed. 13% neither agreed/disagreed and 8% had no view or preferred not to say.
Smoking	**Supported the criteria** (76**%** strongly agreed/agreed) 5% strongly disagreed/disagreed. 11% neither agreed/disagreed and 8% had no view or preferred not to say.
Ovarian reserve	**Mixed views about the criteria** (45**%** strongly agreed/agreed) 19% strongly disagreed/disagreed. 25% neither agreed/disagreed and 11% had no view or preferred not to say.
Previous children	**Mixed views about the criteria** (46**%** strongly agreed/agreed) 33% strongly disagreed/disagreed. 12% neither agreed/disagreed and 8% had no view or preferred not to say.
Previous sterilisation	**Supported the criteria** (55**%** strongly agreed/agreed) 14% strongly disagreed/disagreed). 21% neither agreed/disagreed and 10% had no view or preferred not to say.

*To the survey

When compared with other respondent groups (within the survey):

- **Current or former patient/ service users,** agreed more strongly with the criteria on age of the woman and ovarian reserve. They agreed less strongly regarding criteria on previous IVF cycles, BMI, previous children. They also disagreed more strongly with the criteria on previous sterilisation than other groups.

- **Members of the public,** agreed less strongly with the criteria on age of women, smoking and previous sterilisation. A larger proportion neither agreed nor disagreed with the criteria on ovarian reserve.
- Healthcare staff who responded (inc. general practice, CCG and clinical staff who provided fertility support were more supportive of all the eligibility criteria.
- **Voluntary organisations** agreed significantly more strongly with criteria on smoking and previous sterilisation. There were more mixed views on previous IVF cycles, previous children and ovarian reserve criteria.
- **Those who identified as LGBTQI+** had more mixed views about the BMI criteria and more strongly disagreed with criteria on ovarian reserve, previous children and previous sterilisation.
- **Those who identified as black or of mixed ethnicities,** agreed more strongly with criteria on previous children and previous sterilisation compared with those who identified as white. They agreed less strongly with criteria on ovarian reserve. They disagreed more strongly with criteria on age of woman, previous IVF cycles and BMI compared with those who identified as white.
- **Different age groups held different views about the criteria.** When comparing feedback from those aged 16-45 with those aged 45+, respondents in the younger age bracket more strongly disagreed with criteria on age of woman, and less strongly agreed with criteria around previous IVF cycles, BMI ovarian reserve, previous children and previous sterilisation when compared with those over the age of 45.
- **Those who identified as having a religion** agreed more strongly with criteria on age of woman, previous IVF cycles, smoking, ovarian reserve and previous children, when compared to those who identified as having no religion or being atheist and more strongly disagreed with all of these criteria, expect smoking.

6.2 Comments on the eligibility criteria

The largest volume of comments received were in relation to the previous child criteria. The criteria on ovarian reserve and BMI also received a significant number of comments.

One respondent said:

“I know this treatment does not always work so sensible to try and make sure those who start treatment have a reasonable chance of success”

Another commented:

“*Where no NICE guidance is offered I agree with the NCL approach to funding of treatment*”

Other comments said:

“*Certain things like BMI can be very difficult for people to control, and doesn't mean they're unhealthy, I think a more rounded picture of their health should be taken into consideration not just their BMI, but their exercise and diet. People shouldn't be outright rejected but more put on a programme to start fertility treatments and reduce their weight (if needed)”.*

“Smoking is an addiction and again fertility treatments could still be started as the patient is supported to quit, so a caveat of they must have stopped smoking within 6 months of fertility treatments starting or they will be discontinued.”

“*It is a very personal and emotional subject, but looking to give a fair service to everyone then we have to be firm and subjective*”

6.2.1 Age of woman

A small number of respondents felt a clearer rationale was required for this criterion.

Given some experiences of long waiting times, exacerbated by the pandemic, some were keen to understand the impact of this on this criterion. For example, how are those approaching the age limit affected if they experience a long wait to receive a referral or treatment? One respondent felt there should be a consistent age cut off rather than rather than one for beginning treatment and one for continuing IVF cycles.

Some respondents noted that introducing age limits could result in pressure for women, who may be focused on other aspects of their lives before wanting to consider having children at a later point. Some respondents who attended public meetings noted that some women over 40 were going to Europe to receive treatment and questioned why support wasn't available for those of that age.

6.2.2 Previous IVF cycles

Some individual comments presented conflicting views. Some felt that all women, no matter what their IVF history, should be able to access this on the NHS, whereas others felt that given the costs of IVF and the limitations around its success, meant that having some restrictions due to previous IVF cycles was reasonable.

6.2.3 Body Mass Index (BMI)

A large proportion of those who commented on this criterion felt BMI does not take into account a person's overall health. They also felt that it also doesn't differentiate between different reasons for a person being overweight or obese. There were views that BMI does not take account of muscle tone with muscle being heavier than fat, which could particularly impact women who are shorter who would need to be of lower weight regardless of their general level of health. One respondent felt taking this criteria on a case by case basis would offer a fairer assessment.

It was also felt by some people that BMI, as a concept, was tested and validated on exclusively European men, which is not the demographic of North Central London. A small number of respondents questioned why there was a need for a lower BMI limit. One respondent felt that women who may be bigger bodied may feel further shame from this criterion. One respondent discussed the cultural desirability in some communities for women to be larger and therefore losing weight presents an obstacle that some can't/ don't want to overcome.

One response received suggested that the denial of treatment based on either female or male BMI constitutes an extension beyond the NICE guidance, which recommends that men and women "should be informed" of the risks to infertility associated with obesity or low body weight in women and obesity in men. They also felt that the NICE does not recommend that fertility treatment is withheld on the basis of BMI, but only that women should be informed that female BMI should ideally be in the range of 19–30 before commencing assisted reproduction, and that a female BMI outside this range is likely to reduce the chance of success.

Comments were also received noting the link between some conditions that may impact a person's fertility and their weight, for example, polycystic ovarian syndrome. In such situations, some people felt that the person was facing additional difficulties in addressing their fertility situation.

6.2.4 Smoking

Some people felt that the eligibity criteria on smoking was overly onerous and noted that NICE guidance states that the individual/couple should be warned of the risks of smoking to fertility treatment outcomes and referred to smoking cessation programmes. It was noted that some CCGs place more of a focus on lifestyle recommendations rather than specific eligibility crtieria. Like BMI criteria, the minimum time period for how long couples must have quit smoking presents a further barrier for fertility treatment access, and should rightly be a topic of discussion between couples and their doctors.

6.2.5 Ovarian reserve

Across events and survey responses, it was felt that this criterion was unfair and some questioned whether it was in line with NICE guidelines. A small number of respondents were unclear as to how those with low ovarian reserve would be treated under the policy and whether all or some of the tests in the criteria needed to be met.

A small number of respondents noted; ovarian reserve can fluctuate on a monthly basis meaning there should be no criteria around this, that the criteria was not age stratified as reduced reserve may be expected at some ages, and one clinician noted that ovarian reserve markers were never intended to be used as cut-off criteria for access to IVF. A small number of respondents noted that the age of the woman is not a good indicator of ovarian reserve and suggested AMH and AFC should be used instead.

It was recognised that there was low awareness of conditions related to premature ovarian failure and that clinician's needed better education around how to support with treatment options.

6.2.6 Previous children

Many people were in favour of the position of the draft policy which standardises this criteria, and allows for treatment should one person in the couple (or an individual) does not have a living child.

One respondent was keen to clarify position in relation to children delivered through surrogacy, they noted that in some of these cases the child is not adopted, but is under a parental order. One respondent felt this criteria was more generous than in other areas.

It was felt it that this criteria does not have the same scientific rationale that others do. Noting that adopted children are included within the scope of the previous children criterion, one respondent felt it was then unfair to say that individuals or couples who had adopted were now not eligible for fertility treatment.

One respondent noted that often people are unaware that if you have previous children you are not able to access treatment.

6.2.7 Previous sterilisation

It was felt that people should be able to go back on a previously made decision as circumstances can change. Individuals may have been medically required to undergo sterilisation, or received gender affirming surgery that has sterilised them as a result. Some people felt that in these circumstances, it should not affect their ability to receive fertility treatment on the NHS.

6.2.8 General comments about the criteria

There were differing views on whether the criteria overall were positive or negative – with some feeling they were too arbitrary to deny people access to treatment or, the opposite, that the criteria are evidence-based and offer treatment to those who are most likely to have success.

Small numbers of respondents felt that:

- Success rates of various procedures should be shared.
- The criteria should be more explicit in explaining how the criteria treats female same sex couples.
- The quality of the egg is important as well as ovarian reserve and there is an opportunity to clarify this.
- There should be a reduction in the time trying to conceive for people without a diagnosed fertility problem from 2 years to 1 year for older women.
- There should be an upper age limit for sperm donors or better quality control on donated sperm.
- Criteria should be added around tackling waiting lists and prioritising critical needs, i.e. those about to reach the age limit or other medical issues.
- There was ambiguity in the statement: “women must only be referred to fertility clinics if there is adequate time to complete work up” and this should be clarified to avoid variation in practice.

6.3 Suggested changes to eligibility criteria

Following on from section 6.2, some criteria received more comments than others, therefore only the criteria where respondents suggested specific changes are listed here.

6.3.1 Age of woman

Some people called for a review of the age cut-off with the aim of increasing the upper limit. It was also suggested that the number of cycles offered to women over 40 should be increased.

6.3.2 Body Mass Index

Some people called for a review/ removal of this criteria. People felt that there should be consideration of increasing in the upper BMI limit. It was also felt, to recognise individual efforts to achieve eligibility, that a drop in weight (as with gastric band surgery) could be considered as part of the criteria.

6.3.3 Ovarian reserve

Respondents broadly felt that this criterion should be reviewed and preferably updated to enable greater access to support for those with low ovarian reserve. There was challenge from some around why those with levels lower than those stated couldn’t be offered treatment. It was felt that IVF should be offered anyway and in specific circumstances, such as for women with reduced ovarian reserve due to chemotherapy, would have a reasonable chance of success via IVF, given the chance.

Other feedback supported aligning the criteria to what is within the NICE guidance, meaning no ovarian reserve criteria would apply to women aged under 40.

6.3.4 Previous children

There was a perception from a significant amount of respondents that clarification was needed for clarifying the criterion that is to enable couples where one partner has a previous child to be eligible to access treatment. Many felt the criteria should be adapted so as not to exclude those who had adopted children. Some noted there were many scenarios in which adoption has nothing to do with the need to access fertility treatments, such as adopting the child of a deceased relative. Some felt the criteria should be removed completely.

6.3.5 Previous sterilisation

A number of respondents felt this criterion should be removed.

7 Readability of the policy

7.1 Summary of feedback

The majority of respondents found the policy to be **clear and easily readable**. It was noted that the document was long and technical in some places, despite the glossary. It was broadly felt that those already familiar with the terminology would find the document more accessible than those who didn't.

Many felt an easy read and/or public facing version of the final policy should be produced, to help make the key information accessible. This should focus on explaining what people are entitled to and where/how you seek help.

7.2 Suggestions to improve readability

Many suggestions were made to improve the readability and accessibility of information, including:

- **Drawing out the changes** that had been made to the policy. Although this is discussed in the documentation, some felt this was unclear. A colour coded table about what can and can't be accessed would be beneficial.
- **Presentation of information** – there was mixed feedback about the helpfulness of some of the flowchart pathways in the draft policy. One respondent found the first flowchart confusing. One suggested the flowchart on page 22 needed additional text to clarify specific eligibility. A voluntary sector colleague suggested working with RNIB to ensure diagrams are friendly for those with visual impairments.
- **Translating the policy into different languages –** this would support those for whom English is not their first language.
- **Making the language simpler -** one example was changing the title from "NHS Fertility Review Policy" to "Here's how the NHS can help you conceive a baby". This will support in making information accessible. It will be especially important for those who may be using translation software to view documentation.
- **Making the language more inclusive** –a number of respondents felt some of the language used was hetero-centric and outdated, needing to be more sensitive to the LGBTQI+ community and those not in couples. The overall tone felt paternalistic and judgemental to some. Examples included the language used with regard to HIV. 'HIV positive' is not a recognised term amongst this community and 'people with HIV' should be used instead. Use of 'woman' could also be seen as contentious given that others may approach services for support, including transgender men.
- **Amending the glossary** – a clinical colleague provided useful clarification on some of the definitions within the glossary to improve accuracy and to make the terminology more inclusive. A voluntary organisation also sought inclusion of endometriosis in the glossary as a known cause of infertility.
- **Ensuring accessibility** – for those who cannot read and write, but who want to access fertility treatment. This also includes how the document will be provided, for example clarifying whether it would only be available online.

8 Raising awareness of the policy

8.1 Summary of feedback

The importance of raising awareness of the final policy, once it is implemented, was recognised to ensure those eligible can access services in line with the new policy.

Suggestions were made around how the policy itself could be promoted, as well as sharing key messages within the policy - upskilling those who might refer into the service and those who may be aware they are eligible/ ineligible.

8.2 Suggestions to support with raising awareness

To promote the final policy respondents suggested a range of methods, including:

- **Advertisements** in local newspapers, TV and Radio (including Radio 4's Woman's Hour), council magazines and paid for social media campaigns - targeted at those most likely to be affected/have need of the policy.
- **Posters and information in public spaces**, such as GP waiting areas, assisted conception and gynaecology waiting areas, libraries, sports and social clubs, universities, pharmacies, family planning clinics, children and family clinics, private fertility clinics, on public transport (inc. bus, tube, rail).
- **Sharing of information with local VCS groups** (including those serving minority residents) i.e., fertility charities, Chana (Jewish fertility charity), Fertility Network, RCOG, BICA, BFS, HFEA, Endometriosis UK, Healthwatch, local IVF online forums, Maternity Voice Partnerships, organisations providing alternative therapies and Patient Participation Groups.
- **Sharing of information via community health champions/ social prescribers.**
- **Sharing information via social media**, such as Facebook, Twitter and Instagram including through high profile accounts, podcasts and blogs.
- **Creating videos** and promoting via local personalities and celebrities.
- Asking **local Councillors**, more specifically Health & Adult Social Care Cabinet members to share online.
- **Sending copies** (via direct mailshot) directly to those who have previously enquired about fertility services so that they are able to check their eligibility.
- **Translating the policy** into the top 10 languages in NCL to ensure those whose first language is not English can understand the changes.
- **Utilising search engine optimisation** to ensure the policy can be easily found online**.**

To share the key messages within the policy, suggestions included:

- **Ongoing engagement**
    - To target groups who may previously not have accessed services i.e. non-English speakers, those from ethnic minorities, people with disabilities or communication support needs, members of the LGBTQI+ community and younger people to support in removing barriers to accessing services. This was particularly raised by Healthwatch and other voluntary organisations.
    - To break down taboos around fertility and reproduction in some cultures, enabling people of all backgrounds to get the help they need and understand what the policy means for them. This should include engaging faith and community leaders.

- **Training for healthcare professionals.** Some respondents had an expectation that GPs and other clinicians should be proactively talking through the policy with people, to support in understanding and to highlight if they may be eligible. It was suggested that online training sessions could be held for primary care staff.

9 Service user experience

9.1 Summary of feedback

Due to the nature of fertility services, a small proportion of responses shared personal experiences of accessing services or individual views that are outside of the scope of this engagement process.

Changes to the policy were welcomed, but there was anxiety from service users about how and when the policy would be implemented and the affect this would have on current and future experiences. Particular issues were raised around provision of treatment for female same-sex couples as well as the financial impact of the policy on some groups.

Respondents explored personal challenges with fertility and experiences of using the current system, reflecting the significant impact fertility issues have on mental health. Feedback called for a more holistic approach to providing support.

9.2 Personal experiences and views

Many people recognised that the draft policy would mean an increase in the offer to them for fertility support and were keen to understand how quickly the policy, once agreed, might be implemented. Some explained they were part way through receiving treatment on the NHS and sought advice on whether to defer treatment or to undertake private treatment whilst the policy was being finalised – without impacting their ability to have more treatment on the NHS, if the policy is agreed.

Some were concerned at the impact of COVID on waiting lists and whether any flexibility would be given to those at the upper end of the age limit to continue to have treatment, particularly those who also require surgery for ongoing conditions.

It was recognised that GPs are often the first port of call when seeking fertility support. A number of respondents felt GPs were often unaware of what support was available, with some patients feeling they were not listened to and left struggling to move forward with accessing services. Some felt GPs did not understand the current policies, having been in receipt of incorrect advice. As mentioned elsewhere in this report, it was felt key that training is provided for GPs and wider healthcare professionals so that they can understand the referral pathway, eligibility criteria and timelines for treatment. It was also felt they should be proactively discussing the policy with eligible patients, considering where pre-conception advice could be useful (and signposting to other services, e.g. smoking cessation or weight loss services). Some also noted that diagnostic tests in primary care often took a long time, which delayed the receipt of treatment and had other knock-on effects.

Some commented on patient choice in terms of selecting a hospital for treatment, and asked whether this would be permitted going forward. Respondents recognised that currently this usually depends on where you are registered with your GP but recommended that in future patients be able to choose where they are able to access treatment.

Many respondents stressed the impact fertility issues have on mental health and believed not being able to access treatment could lead to an increase in usage of mental health services. It was recognised that, for people at any stage of seeking support for fertility issues, there should be proactivity in signposting to mental health services for psychological support. Several respondents

recognised the benefit of pre-conception counselling and counselling throughout their fertility journey – especially if treatments are unsuccessful. One respondent felt it was important to breakdown the stigma around seeing a counsellor especially for different cultural groups. In some providers, the co-location of fertility and maternity patients in joint waiting rooms was felt, by one respondent, to be something which needs to be addressed.

Many referred to inequalities in the policy meaning the LGBTQI+ community and single women, under the draft policy, would be required to self-fund a significant amount of treatment before being able to access NHS services. This has, and would have, a number of impacts on these groups, including: financially – with the cost of these treatments often exceeding £10,000, emotionally - having to wait to receive treatment on the NHS knowing they are being treated differently than heterosexual couples and time – the delay in accessing treatment adds a time pressure to the process and increases the age of the potential mother. All of these issues present barriers for these groups in starting a family.

It was recognised that funding of private treatment is not only an issue for the LGBTQI+ community and single women. It was felt there should be greater consideration of those from lower income families who cannot afford to undergo private treatment. Some suggested that introducing a means tested system may support access. Several respondents questioned why fertility services should be/were funded on the NHS, with concerns that other health services should be prioritised for funding instead.

Some individual views commented on the need to focus on the best interest of the child and not on the desire of individuals to become parents. One respondent shared their lack of support for treatments requiring eggs or donor sperm. Another was concerned that some treatments enabled scenarios where children might not have a relationship with both biological parents.

10 Next steps

The Fertility Policy Development team are currently considering the comments received during the engagement. Where appropriate, further work will be undertaken to further research issues raised and we will discuss them with our internal stakeholders, such as the Clinical Reference Group, key consultants in the arena of fertility and with our clinical colleagues on the Governing Body. We are also seeking legal advice on some matters to ensure that our Policy complies with our equality duty and with our legal duties generally.

Alongside this, we are also planning the implementation of the finalised policy. This involves activities such as ensuring that our provider organisations are ready and prepared to deliver services according to the policy, that the policy is communicated effectively to the public and to our clinicians, and that all necessary resources are made available to deliver the policy.

Additionally, we will also need to update our Equality Impact Assessment and our Quality Impact Assessments to align with the final policy.

The approval of the final policy will be made by the NCL CCG Strategy & Commissioning Committee (subject to timelines and any changes in governance should the transition to the NCL Integrated Care Board need to be considered).

According to current planning assumptions, we are expecting the final policy to be approved in late May 2022. We cannot yet confirm exact dates for the “go-live” of the new policy, but again, given current planning assumptions, we are expecting implementation to commence in summer 2022.

If you would like to keep up to date with news of our policy development you can email the Fertility Policy Development Team who will ensure that you receive future updates. The team can be contacted by:

Email: nclccg.fertility-review@nhs.net
Telephone: 020 3688 2038

Appendices

Appendix 1 - List of events held

Table 6: List of events held

Date of meeting	Meeting	Target audience	Number of attendees	Borough
26.11.21	Joint Health Overview Scrutiny Committee (JHOSC)	NCL JHOSC members and officers	8	All NCL
08.12.21	NCL Clinical Advisory Group	NCL Medical Directors, Co-chair Health and Care Cabinet, ICS Chief Nurse & NCL Senior Nurse representative	11	All NCL
09.12.21	Enfield Saheli	A registered charity for women who are isolated, discouraged or depressed	35	Enfield
09.12.21	Haringey Engagement Network meeting	Voluntary organisations supporting a range of residents. Those in attendance represented carers, local people, LGBTQI+ & BAME communities, vulnerable people and those with mental health issues. Healthwatch was also in attendance.	24	Haringey
09.12.21	Barnet online public meeting	Members of the public from Barnet	1	Barnet
09.12.21	Enfield Online Public meeting	Members of the public from Enfield	1	Enfield
13.12.21	Camden Patient & Public Engagement Group (CPPEG)	Representatives from local VCS groups (Healthwatch, Age UK, Voluntary Action Camden, Camden Carers Service and GP PPG members	16	Camden
14.12.21	Enfield Voluntary & Community Stakeholder	Voluntary organisations supporting a range of residents. Those in attendance represented	14	Enfield

	Reference Group	LGBT communities, women, older people, parents and children with special needs and carers and those from different races. Healthwatch was also in attendance.		
14.12.21	Camden Online Public meeting	Members of the public from Camden	4	Camden
01.01.22	Fertility Network UK	Members of the network (people with lived experience and representatives from the Donor Conception Network & CHANA (Leading fertility support organisation for the Jewish community)	6	NCL wide
06.01.22	Primary Care Silver	General Practice - clinical and non-clinical staff	52	NCL wide
10.01.22	Weekly Webinar	NCL GB GPs & Clinical Leads	15	NCL wide
12.01.22	Haringey online public meeting	Members of the public from Haringey	7	Haringey
13.01.22	Weekly GP Webinar	GP Webinar for NCL Practices (clinical and non-clinical staff)	80	NCL wide
13.01.22	NCL primary care clinical leads weekly catch up	NCL primary care – clinical leads catch up	8	NCL wide
17.01.22	Islington online public meeting	Members of the public from Islington	1	Islington
20.01.22	NCL wide online public meeting	Members of the public from across NCL	4	All NCL
20.01.22	Camden Parents Forum	Parents in Camden	5	Camden
20.01.22	Haringey LGBTQI+ Community Network	Those from the LGBTQI+ community	24	Haringey
29.01.22	NCL wide online public meeting	Members of the public from across NCL	5	All NCL
08.02.22	Focus group	Residents whose country of origin is not the UK	10	All NCL

Appendix 2 - List of third sector organisations who responded and assisted in raising awareness of the Draft Fertility Policy

Age UKs in Camden and Enfield	Alexandra Park School
Barnet Faith Leaders Forum	BPAS Fertility
Bridge Renewal Trust	Camden Carers Service
Camden Disability Action	Camden Faith Leaders Forum
Camden Parents Forum	Carers First (Haringey)
Citizens Advice Haringey	Community Barnet
Defend Haringey NHS	Eastern European and Roma Community network
Eastern European Forum	Endometriosis UK
Enfield Carers	Enfield Faith Leaders Forum
Enfield LGBT Network	Enfield over 50s Forum
Enfield Racial Equality Council	Enfield Saheli
Enfield Voluntary Action	Enfield Women's Centre
Fertility Network UK (inc. Donor Conception Network & Chana Charity Ltd)	Forum+ (LGBT network for Camden & Islington)
Future Wood Green BID	Galop
Haringey Faith Leaders Forum	Haringey Over 50s
Haringey Recovery Service	Haringey Wellbeing
Healthwatch organisations in Barnet, Camden, Enfield, Haringey and Islington	Homes for Haringey
Islington Faith Leaders Forum	Jacksons Lane
METRO Charity	Mind in Haringey
NCL Community Members	Ner Yisrael Synagogue
Our Voice	Phoenix Family Support Services
POhWER	Reach & Connect
Samafal Families Association	TCV Haringey
The LGBT Mummies Tribe	Thinking Space
Voluntary Action Camden	Voluntary Action Enfield
Voluntary Action Islington	Wise Thoughts

Appendix 3 – Full demographic profile of respondents

Please note that there were occasions when respondents did not disclose all of their demographic data

Table 7: Respondent location - where disclosed

Borough	Number of survey respondents	Number of event attendees	Percentage
Barnet	27	3	**14%**
Camden	23	25	**23%**
Enfield	11	60	**33%**
Haringey	18	32	**23%**
Islington	13	1	**7%**

Table 8: Respondent age - where disclosed

Age group	Number of survey respondents	Number of event attendees	Percentage
16-18	2	0	**1%**
19-24	2	0	**1%**
25-34	29	14	**30%**
35-44	36	16	**37%**
45-54	11	2	**9%**
55-64	11	5	**11%**
65-79	11	2	**9%**
80+	2	0	**1%**

Table 9: Respondent ethnicity- where disclosed

Self-identified ethnicity	Number of survey respondents	Number of event attendees	Percentage	NCL
White: Welsh/English/Scottish/Northern Irish/British	58	46	**56%**	**White 63%**
White: Irish	6	0	**3%**	
White: Gypsy or Irish Traveller	0	2		
White: Any other White background	13	2	**8%**	
Mixed: White and Black Caribbean	0	0		**Black and other ethnic minority groups 37%**
Mixed: White and Black African	0	0		
Mixed: White and Asian	3	0	**2%**	
Mixed: Any other mixed background	2	0		
Asian/Asian British: Indian	6	0	**3%**	
Asian/Asian British: Pakistani	2	2	**2%**	
Asian/Asian British: Bangladeshi	1	2	**1%**	
Asian/Asian British: Any other Asian background	1	4	**3%**	
Black or Black British: Black – Caribbean	1	3	**2%**	
Black or Black British: Black – African	6	3	**5%**	

Black or Black British: Any other Black background	2	11	**6%**	
Other ethnic background: Chinese	0	0		
Other ethnic background: Any other ethnic group	1	9	**5%**	

Table 10: Respondent gender- where disclosed

Gender	No. of survey respondents	No. of event attendees	Percentage	NCL
Female (including trans woman)	76	56	70%	**51%**
Male (including trans male)	24	18	22%	**49%**

Table 11: Sexual orientation - where disclosed

Sexual orientation	No. of survey respondents	No. of event attendees	Percentage
Bisexual	7	1	**5%**
Gay	2	3	**3%**
Heterosexual	78	45	**83%**
Lesbian	5	5	**7%**
None of the above	3	0	**2%**

Table 12: Respondent disability - where disclosed

Do you consider yourself to have a disability?	No. of survey respondents	No. of event attendees	Percentage
Yes	14	0	**13%**
No	87	3	**86%**

Table 13: Respondent religion or belief - where disclosed

Religion or belief	No. of survey respondents	No. of event attendees	Percentage
Atheist	5	2	**6%**
Buddhist	1	0	**1%**
Hindu	2	1	**2%**
Christian	27	9	**29%**
Jewish	14	0	**11%**
Muslim	5	9	**11%**
No religion	40	3	**35%**
Any other religion	4	0	**3%**
Sikh	1	0	**1%**

Appendix 4 – Feedback themes by prevalence

Table 14: Support/ non-support for the policy

Comment/ theme	Frequency of response in survey	Frequency of response in events/focus groups	Frequency of response in formal written responses
Support - believe policy gives levelled up provision across the boroughs	37	4	2
Support - fair and reasonable policy in line with NICE guidance	27		2
Support - agree with increasing cycles in-line with nice guidelines	19		
Support - reduce inequity of treatment/ postcode lottery	10	2	
Not supportive - fertility services should not be provided on NHS at all	6		
Not supportive - current offer for LGBTQI+ people (including same-sex female couples) is discriminatory	6		
Not supportive - Waiting after 2 years of naturally trying to conceive for patients who do not have a confirmed explanation for their infertility is unjust	6	3	
Not supportive - current policies unfair	9		
Not supportive - same- sex provision – wrong that female same sex couples need to undertake 6 rounds of self-funded IUI before receiving NHS treatment	11	1	
Not supportive- waiting 2 years for those over 35 with unexplained fertility issues is too long	6	1	
Not supportive – language used. Document is heterocentric/ needs testing with LQBTQ+ community	5	1	
Not supportive- language used. In regard to HIV we should be using “people with HIV”	3	1	
Not supportive - IVF is promoted over IUI because of the profits margins	2		
Support - would be able to have fertility treatment using donor sperm/ eggs	3		
Support – women with low ovarian reserve having access	2		
Support - hope it reduces waiting time	2		
Not supportive - there should be funding for people with unexplained fertility	2		
Not supportive - there should be no limitations on couples who have previously undergone IVF	2		
Support – current offer for same-sex couples is equal to heterosexual couples	2		

Not supportive - what assessment criteria are there that heterosexual couples have tried for two years	2	1	
Not supportive - how has the conclusion been reached that same sex couples should be financially disadvantaged	2	1	
Not supportive - CCG are deviating from NICE guidance to require self-funded IUIs	2	1	
Not supportive - conflict of interest as some NHS IVF practitioners also run private clinics - minimal open tendering for fertility treatment contract and ability to FOI	2		
Not supportive – same sex couples are not put through the same process as heterosexual couples	3	1	
Support - NHS funding for IVF using donated eggs (for eligible patients on waiting list) will make egg donor IVF accessible to those who cannot afford it privately	1		
Supportive - IUI is patient friendly and compatible with the huge patient diversity covering the CCGs in London	1		
Not supportive - 97% of all eggs retrieved are wasted and half of them go into the freezer and most thrown away - a waste of public and patients monies.	1		

Table 15: Eligibility criteria

Comment/ theme	**Frequency of response in survey**	**Frequency of response in events/focus groups**	**Frequency of response in formal written responses**
General comments			
Comment - There should be no limitation on funding for couples who have had private treatment elsewhere	4		
Comment - criteria too arbitrary to deny people access to treatment	3		
Comment - criteria are evidence-based and offer treatment to those who are most likely to have success	3		
Comment- quality of the egg is important as well as reserve	2		
Comment - Reduce the time trying to conceive from 2 years to 1 year	2		
Comment - having to have three miscarriages before you are eligible is hard		1	
Comment - success rates should be shared		1	
Comment - criteria should be added around tackling waiting lists/ critical needs	1		
Comment - not clear how criteria treats same sex couples - needs to be more explicit	1		

Comment - Women must only be referred to fertility clinics if there is adequate time to complete work up. ' in eligibility criteria is ambiguous	1		
Ovarian reserve	**Frequency of response in survey**	**Frequency of response in events/focus groups**	**Frequency of response in formal written responses**
Comment - Ovarian reserve criteria unfair/ not in line with NICE guidelines	11		
Change - Ovarian reserve criteria – review/ reduce and offer IVF anyway	4	3	
Change - Ovarian reserve – levels seem high. Challenge why people with levels lower than those stated can't be offered treatments	4	2	
Comment - Ovarian reserve – awareness of this condition needs to be raised with healthcare professionals	2		
Change - Ovarian reserve - requirement for women to meet all ovarian reserve criteria for IVF should only apply to those over the age of 40 (in line with NICE guidance)	2	4	
Change - young women with reduced ovarian reserve due to chemo would do well on IVF given the chance	1		
Comment - ovarian reserve markers were never intended to be used as cut-off criteria for access to IVF	1		
Comment - Ovarian reserve – explain how women with low reserves will be treated	1		
Comment - Ovarian reserve - this fluctuates on a monthly basis, there should be no limitations on this	1		
Change - Ovarian reserve – not age stratified. Reduced reserve may be expected at some ages	1	1	
Age of the woman is not a good indicator of ovarian reserve. Rather, AMH and AFC are more indicative of ovarian reserve.	1		
Comment - unclear whether you need to meet all of the tests for this	1		
IUI/IVF	**Frequency of response in survey**	**Frequency of response in events/focus groups**	**Frequency of response in formal written responses**
Change - no limitations in funding for couple who have had private rounds of IVF	9		
Comment - IVF is a very expensive and mostly unnecessary procedure with high failure rates	1		
Comment – all women, no matter IVF history, should be allowed to have it on the NHS	1		

Change - Implement up to 3 full cycles of treatment as per NICE guidance.	1		
Comment - confusion around previous IVF cycles, or previous embryo transfers - or indeed, what the difference was	1		
Previous child	**Frequency of response in survey**	**Frequency of response in events/focus groups**	**Frequency of response in formal written responses**
Change - Previous children criteria -review/ enable couples access where one partner has a previous child	30	3	
Change - remove previous child criteria	7		
Change - Previous children - an adopted child should not be recognised as a biological child	6	4	
Comment - Previous children criteria is more generous than in other areas	1		
Comment - Previous children - agree	1		
Comment - Previous children - clarify position in relation to children delivered through surrogacy as technically they are not adopted it's a parental order		1	
People are unaware of this criteria			1
Previous sterilisation	**Frequency of response in survey**	**Frequency of response in events/focus groups**	**Frequency of response in formal written responses**
Change - Previous sterilisation – should not be a criteria/ people should be able to change their mind	6		
Comment - if a person has been medically required to undergo sterilisation, or has received gender affirming surgery that has sterilised them as a result, this should not affect their ability to receive fertility treatment on the NHS.	1		
BMI	**Frequency of response in survey**	**Frequency of response in events/focus groups**	**Frequency of response in formal written responses**
Comment - BMI - a binary measure not taking into account a persons overall health/ doesn't differentiate between different reasons for weight	12		1
Change - BMI – review/ raise	6	3	
Change - BMI – criteria should also consider a drop in weight as indicatory of eligibility	1		
Comment - BMI – agree	2		
Comment - BMI - tested and validated on exclusively European men, which is not the demographic of North Central London	3		

Comment - BMI - big bodied women may feel shamed by this criteria	1		
Comment - why is there a need for a lower BMI limit	2		1
Comment - important to consider cultural reasons for being overweight = desirability			1
Age of woman	**Frequency of response in survey**	**Frequency of response in events/focus groups**	**Frequency of response in formal written responses**
Change - Age of woman – review cut off and increase	16		
Change - Age of woman - women under 40 should have more options	1		
Change - Age of woman – provide more background on rationale for cut-off	3		
Change - Age of woman – increase number of cycles available for women over 40	2		
Comment - consider the impact of waiting lists on age cut-off	1		
Change - temporarily increase in light of impact of COVID on waiting lists	2		2
Should be a consistent age cut off rather than rather than one for beginning treatment and one for continuing IVF cycles	1		
Smoking	**Frequency of response in survey**	**Frequency of response in events/focus groups**	**Frequency of response in formal written responses**
Comment - Smoking – agree	3		

Table 16: Policy

Comment/ theme	**Frequency of response in survey**	**Frequency of response in events/focus groups**	**Frequency of response in formal written responses**
Conditions/ communities missed or underserved			
Change- - Equality of access for homosexual couples and single women compared to heterosexual couples	11		1
Comment - clarify if someone has had some NHS treatment, and since gone privately, can they go back for further NHS treatment once this policy is approved	2		

Comment - will current patients benefit from the new policy/ clarify how current patients will transition to new policy	2	4	
Comment - does not account for those with endometriosis whose ovarian reserve would not meet criteria	1		
Comment- does not account for women for whom there is both e.g. vaginismus and male fertility issues	1		
Comment – same sex couples to be able to use AI at home	1		
Comment - clarify what your criteria is for women presenting with a trans male partner	1		
General comment - Separate policy for single females and same sex couples to get insemination on the NHS and ensure safe sperm procurement	1		
Change - need to be more inclusive of the rights of transgender individuals	2		
Comment – need to be more inclusive in giving opportunities for disabled people.	1		
Comment - No consideration for those with poly-cystic ovary syndrome		1	1
Comment – more flexibility needed for looking at BMI	1		
Comment – more provision for surrogacy for people from the LGBTQI+ community	1		
Comment – more time to be given for storage of sperm and eggs.	1		
Comment - does not cover what happens if you lose the baby			1
Points of clarification	**Frequency of response in survey**	**Frequency of response in events/focus groups**	**Frequency of response in formal written responses**
Comment - clarify if there is funding for same sex female couples to identify fertility issues, which would then make them eligible for fertility treatment	5	2	
Change - clarify that for patients who pay the immigration surcharge; assisted conception services are not available for free	3		1
Comment - clarify definition of a cancelled cycle. Currently based on if a collection occurs. But what if they do the egg collection but don't do a transfer. Should be a clause for when that occurs so they don't lose out	2		

Comment – Gay tax for people trying to conceive is unfair	2		
Comment - clarify NICE guidance includes home insemination in 'artificial insemination'; it's not clear why you are discounting this/ will the CCG fund this	2	2	
Comment - clarify definition of a cycle and entitlement	1		
Comment- if either patient is paying a surcharge, do neither become eligible?	1		
Comment - clarify exploratory measures on offer within NHS prior to IVF to test infertility including hycose and other diagnostic procedures that may offer diagnose or eliminate infertility concerns	1		
Comment - clarify what number of cycles are funded - Is that 6 embryo transfers? If somebody had 2 embryos transferred at the same time would that count as 1 or 2		1	
Comment - clarify if using one low quality embryo with low chance of success would count as one of the attempts		1	
Comment - clarify if a women goes through a simulated cycle and produces quite a number of embryos, exhausting more than her 6 embryos, does she need to pay for further transfers if she has more cycles?		1	
Comment - clarify whether recipients who use the paid services of a donor recruitment agency are not excluded from the policy			1
Need standard definitions about what we call a good embryo		1	
Impact of implementing the new policy	**Frequency of response in survey**	**Frequency of response in events/focus groups**	**Frequency of response in formal written responses**
What is the likely implementation timeline for this policy?		1	
Need to streamline testing in primary care to save time		2	
Important to align not just across NCL, but regionally		1	
Why is there not just a national policy	1	1	1
Low awareness of services available from ethnic minority and LGBTQI+ communities			1

Table 17: Services provided

Comment/ theme	Frequency of response in survey	Frequency of response in events/focus groups	Frequency of response in formal written responses
IVF with or without ICSI			
Change - 3 full cycles should be provided as recognised and defined by NICE	2		
Change - CCG should fund treatment using frozen as well as fresh eggs	1		
Comment - IVF causes lots of multiple births which is risky and costly	1		
Change - Review IVF/ICSI – and whether a natural cycle should be funded	2		
Change - define -explanation of a cycle entitlement is not clear, as it is displayed as if it is 3 cycles when in fact it is partial cycles	1		
Comment - why can't IVF be offered for those who have physical or psychosexual cause for their infertility as IUI may not be clinically appropriate (or tolerated) for all in this group			1
Change - should not be offering IVF to immune compromised people	1		
Can the couple be offered IVF if their physical disability or psychosexual problem prohibits them from having IUI?			1
Comment – single women should be able to access services/ be offered IVF	4		
Change- NHS funded treatment available to same sex women of any age	1		
Recognises this improves the offering some boroughs	1		
Not all IVF providers in NCL are able to offer ACT with donor gametes	1		
IUI	**Frequency of response in survey**	**Frequency of response in events/focus groups**	**Frequency of response in formal written responses**
Change - reduce number of privately funded cycles of fertility treatment required for queer or single people or be replaced by a means-tested figure	3		
Change - Same sex couples shouldn't have to self fund IUI first, as heterosexuals don't have to. Discrimination.	13		
Comment - IUI should be funded for all women under going fertility treatment	6		
Comment - IUI it is not clear how many cycles the NHS will fund and at what point		1	1

Comment - NCL made of diverse communities. Research has concluded ethnic people and black population were less able to receive IVF. This is because they are less willing to try complex technologies and prefer less risky minimalist IUI type treatments.	1		
Comment - Cost effectiveness of IUI over IVF needs to be factored in so that more women can become pregnant with the least intrusive and least risky option of IUI	1		
Comment - IUI needs to be stimulated for it to work	1		
Comment - align with national guidance on IUI for same sex couples	1		
Comment - IUI using partner sperm - why should heterosexual couples who cannot have vaginal intercourse for medical reasons? have to pay for private IUI first	1		1
Comment - Clarity on why IUI is not routinely funded for people with unexplained infertility, mild endometriosis or mild male factor infertility. This is a huge cost	1	1	
Up to six cycles of STIMULATED IUI using partner sperm is funded except where there is very severe male fertility problem or there is bilateral tubal blockage	1		
IUI is ROUTINELY funded for people with unexplained infertility, mild endometriosis or mild male factor infertility except in the following circumstances: severe male factor infertility or bilateral tubal blockage	1		
Policy should be to use IUI first before IVF	1		
Change - please go for IUI (6 cycles first) then IVF cycles (3 cycles become feasible where needed)	1		
Change - please include IUI (intrauterine insemination) for most cases (husband sperm and female partner) as the treatment mode is least invasive, less risky and very cost effective	1		
Comment - Cheaper to have an IUI baby compared to an IVF baby	1		
Comment - Discriminatory -IUI criteria same sex couples and single women	7	2	
Comment - unlikely people would have 6 rounds of IUIs in 6mths more likely to be 12 months or more. Age is a factor in declining fertility this puts same sex couples at a significant disadvantage.	2	1	
Change - IUI needs to be provided as a first line treatment option.	1		
Change - sexual orientation should not be the determining factor as to whether a couple must self-fund IUI or not	5		
Change - LGBT couples (after having to self fund 6 cycles of IUI) should not be offered 6 more cycles of IUI (!) on the NHS before being offered IVF. This is	1		

not in line with NICE guidelines and is a major burden			
Comment - Why can't women who require ovulation induction have IUI-D?			1
Cryopreservation	**Frequency of response in survey**	**Frequency of response in events/focus groups**	**Frequency of response in formal written responses**
Cryopreservation - clearer wording to explain years that NHS would fund freezing for IVF (including for those undergoing cancer treatment)	4		
Cryopreservation – provision of this is positive	1		
Cryopreservation - the age criterion for women is sensible	1		
Cryopreservation – needs to be looked into as it is costly and wasteful	1		
Cryopreservation - expand eggs preservation more widely	1		
Cryopreservation - if a person has frozen eggs when younger, and then requires fertility support - there should be an option to mix care	1		
Policy needs to reflect that the NHS had recently increased the storage limit for eggs / sperm to 55 years	1		
What provision is made for recipients who wish to use stored donor eggs that are only available in a private unit that does not have a contract with the CCG? This is particularly pertinent for ethnic minorities where they may have no reasonable chance of finding a suitable donor.			1
Cryopreservation is something that young people should be made more aware of so that fertility is thought of at an earlier age	1		
Change - suggest for those without a womb (MRKH) there is funding for ovarian stimulation and cryopreservation but not surrogacy	1		
Greater education and support is needed for couples with cancer diagnosis around freezing of gametes and better provision of freezing capabilities amongst different regional centres.	1		
All women should be funded to cryopreserve embryos so that they can be used in subsequent private cycles if they want another child	1		
Include a surgical condition. For example: Significant symptomatic ovarian endometriosis needing ovarian surgery, or recurrent ovarian endometriosis/ cyst that can decrease the ovarian reserve drastically.	1		
Clearer information about what happens to stored materials after time runs out	1		

Cryopreservation of gametes for gender reassignment isn't a medically necessary treatment and someone undergoing gender affirming hormone treatment can delay theirs in order to undergo FP.	1		
Sperm washing	**Frequency of response in survey**	**Frequency of response in events/focus groups**	**Frequency of response in formal written responses**
Change - HIV positive individual will not pass on the virus to HIV negative person through sexual intercourse (if on the correct medication) and this information should be included	2	1	
Man should be compliant with Anti retroviral therapy before being considered for sperm washing	1		
Comment - Sperm washing has limited evidence in people living with HIV and can be stigmatising	1		
Comment - after sperm washing couples have to choose between 6 cycles of IUI or IVF. Why are they funded for less than those using donor sperm?			1
Comment - not equality of access to sperm washing for gay men			1
Assisted conception and surrogates	**Frequency of response in survey**	**Frequency of response in events/focus groups**	**Frequency of response in formal written responses**
Comment - assisted conception treatments involving surrogates not being funded is disappointing and support should be offered	7		1
Comment - consideration of young cancer patients being funded the embryo transfer costs to a surrogate	1		
Change - same sex couples should be eligible for surrogacy treatments in order to be given an equal opportunity as heterosexual couples to become parents.	2		
Comment - better quality at home insemination for same sex couples, such as advice, fertility drugs, funded access to sperm if needed	1		
Change - . ICI is not recommended by NICE and I suggest reference to it is removed			1
IVF with donor eggs	**Frequency of response in survey**	**Frequency of response in events/focus groups**	**Frequency of response in formal written responses**
Comment - greater clarity needed on funding and use of donor eggs and donor sperm	3	1	1
Offer to pay for donor sperm and donor eggs	1		

Comment - Funding of donor eggs for IVF is positive	3		
Frozen eggs to be used for donor IVF from the start	1		
What checks will there be to ensure there are no mitochondrial defects in donated eggs			1
IUI and IVF using donor sperm	**Frequency of response in survey**	**Frequency of response in events/focus groups**	**Frequency of response in formal written responses**
Change - should not expect couples to self fund iui with donor sperm	3		
Comment - should be an upper age limit for sperm donors/ quality control on donated sperm	1	1	
Other	**Frequency of response in survey**	**Frequency of response in events/focus groups**	**Frequency of response in formal written responses**
Comment - male fertility issues should be funded	1		
Change - Introduce ovarian reserve function testing before embarking on the journey	1	1	

Table 18: Concerns

Comment/ theme	**Frequency of response in survey**	**Frequency of response in events/focus groups**	**Frequency of response in formal written responses**
The policy does not pass an equality test for same sex couples, including those who have transitioned, and is discriminatory	7		
POC could be who would be detrimentally affected by BMI	1		
Allowances for people without access to funding for IUI in the first place particularly same sex couples	2		
How will patients be affected if services continue to be accessed on a location basis	1		
Discriminates against single women and couples with psychosexual issues	2		
Female infertility is less supported and funded than male infertility		1	
Gay male couples find it very difficult to have a biological child.		1	
It is not totally clear which “fertility problems” are eligible for NHS funding.		1	

Funding is falling in an inequitable way across the age groups.		1	
Is there funding available to implement the policy/ consider how you are funding fertility services	1	4	
How are we encouraging access for black and minority ethnic groups/ awareness of the policy		3	

Table 19: Readability

Comment/ theme	**Frequency of response in survey**	**Frequency of response in events/focus groups**	**Frequency of response in formal written responses**
Additional information/ resources required			
Need an easy-to-read version	11	1	5
Comment - clarify what changes have been made to the policy - could this be drawn out	5		
Presentation – included colour coded table to explain what you can and can't access	1		1
Language	**Frequency of response in survey**	**Frequency of response in events/focus groups**	**Frequency of response in formal written responses**
Comment - language in the policy is not gender inclusive and comes across paternalistic and judgmental	7		
Comment- language used throughout the policy using 'woman' here is contentious given that others may approach for support, including trans men	2		1
Comment - Glossary amends - Consider using storing instead of freezing, as technically, the correct word is vitrification. Consider making this change throughout the document.			1
Change - Glossary amends - ovarian reserve definition is inaccurate, as egg number does not reflect the chance of natural pregnancy, but it does for IVF.			1
Change - Glossary amends - preimplantation - embryos have never been in the uterus, so they can't be transferred "back".			1
Change - Glossary amends - Primary ovarian insufficiency the preferred term, which is premature ovarian insufficiency. Also the age cut off is 40, not 45 yrs.			1
Change - Glossary amends - Supernumerary embryos are created from a fresh IVF cycle			1

that are left over after an embryo(s) has been transferred			
Change – a quick look up for common types of fertility needs is required.	1		
Change - Glossary amends - Unsuccessful cycle of IVF/ ICSI result in a failure to become pregnant as conception has already happened			1
Readability	**Frequency of response in survey**	**Frequency of response in events/focus groups**	**Frequency of response in formal written responses**
Easy to understand	23		
Fairly easy to understand	9		
For those familiar with the terms/ process it is easy to read but for others it's not	8		
Not easy to understand	3		
Readability - needs to be edited to read more easily and logically	2		
Assume clinician will take patients through the document	1		
Readability - long	1		1
Readability – clearly organised and easy to reference	1		
Presentation - tables and flow charts helpful	1	1	
Presentation- flow chart unhelpful	1		
Changes between previous policies and this one are clear		1	
Use easy to understand language	2	1	
Some glossary terms inaccurate			1
Flowchart on page 22 indicates that couples using donor sperm for male factor issues, get 6 cycles of funded IUI-D but then have to self-fund another 6 cycles of IUI-D before being able to have funded IVF. Add this to the text for clarify			1
Simple content online is good for non-English speakers making use of translation tools on their mobiles		1	
Information provided in a way that make sense to local people not just the NHS through using accessible language		1	1
How can this be made accessible for people who cannot read or write			1

Check with RNIB for guidelines on readability of the flowchart			1

Table 20: Raising awareness

Comment/ theme	Frequency of response in survey	Frequency of response in events/focus groups	Frequency of response in formal written responses
GP waiting room/ booking system/website/PPGs	25	1	2
Via infertility social media (including high profile accounts) and blogs	12	1	
Paid for social media campaigns	2		
Assisted conception/ fertility clinic waiting room	8	2	
Gynaecology waiting room	7	1	1
Cervical smear			1
Feature in local borough-based newspapers	6		
GP to directly share/discuss with patient	9	1	
CCG website	7	1	
Libraries	5		
Fertility networks and charities such as RCOG, BICA, BFS, HFEA, Endometriosis UK and Chana	6		
Local support groups/ voluntary organisations/ Healthwatch/ community health champions/ social prescribers	3	4	1
Online fertility forums	2		
Pharmacy	2		
Letter to/ contact with all affected patients	2		
Training around the policy for healthcare staff (inc. GPs)	4	3	2
Direct mailshots (inc. via council bills)	2		
Translation to other languages	2	1	4
Public transport (inc. bus, tube, rail)	2		
Further engagement	2	1	
Local authority	2	1	
Consultant to share/discuss with patient	1		
Local councillors	1		
Radio	1		
Public spaces such as social and sports clubs etc.	1	1	

Targeting groups who may previously not have accessed services i.e., non-English speakers, ethnic minorities, people with disabilities or communication support needs, members of the LGBTQ+ community and younger people	1	1	5
Engage faith and community leaders to reduce stigma	1	1	1
Ensure CCG website has search engine optimisation so the policy can be found	1	1	
Via Maternity Voice Partnerships	1		
Promote via alternative therapies		1	
University/ colleges	1	1	
Family planning clinics		1	1
Children and family clinics		1	1
UK wide page storing all fertility policies searchable by postcode	1		
Patient engagement groups	1		
Video on website	1		
Local Newspaper publication	1		
Postal campaign	1		
Podcast	1		

Table 21: Actions

Comment/ theme	**Frequency of response in survey**	**Frequency of response in events/focus groups**	**Frequency of response in formal written responses**
Create a companion document that gives context to what the journey might be like, what support is available and what other investigations that people need to go through before this policy applies and the timescales	3	2	
Ongoing engagement with local communities (including HIV support organisations) to understand difficulties - particularly those accessing services at a lower rate, such as: ethnic minority backgrounds and the LGBTQ+ community	4	1	2
Offer intensive training to all health care professionals on the new policy and pathway (including HIV guidance)	2	3	
Monitor uptake of fertility services across NCL to ensure that this service is being equitably accessed by protected characteristics and practice			2
Monitor where referrals come from			1
Monitor success rates and performance manage individual Trusts and offer contracts accordingly	1		
Take account of the local population needs and mindsets and taper treatment services	1		

Signposting to support (i.e., counselling) and other services for if the NHS can't help	1	2	
Adjust policy when new research becomes available	1		
AI to be allowed at people's home	1		
Increase age limits	1		
Online eligibility questionnaire that can be embedded on websites and help prospective patients easily understand whether they are eligible for treatment (and the type of treatment).	1		

Table 22: Personal experiences/ views

Comment/ theme	**Frequency of response in survey**	**Frequency of response in events/focus groups**	**Frequency of response in formal written responses**
Often the GP does not listen / does not have time to listen to the patient	3	1	
Personal experience/view - Previous negative experience of accessing NHS fertility service	2		
Personal experience/view - Not supportive of any treatments that require donor eggs or donor sperm	1		
Should offer patient choice and not access services dependent on which GP practice you are registered with	2	1	
Personal experience/view - Males have very little say in what happens in women's bodies	1		
Personal experience/view - Give every woman an opportunity to have a baby no matter what their sexual orientation or their relationship status	1		
Treatment should be provided as per a patient's expectation and not forced on them	1		
Policy should focus on the best interests of the child, not the desire to become a parent	1		
More money needed for the NHS	2		
Policy should be child oriented not parent oriented	1		
Children conceived via IVF excludes them from relationship with both parents	1		
Patients seeking IVF should be required to undertake DBS	1		
Current policies do not provide enough cycles in line with NICE guidelines	2		
COVID recovery - mental health and cancer services prioritised above fertility	2		

Any process to enable people to become parents should be welcomed	2		
Comment – support should be given on lifestyle factors to support eligibility	5	4	
Comment - mothers should commit to abstaining from recreational drugs and alcohol during pregnancy and treatment	1		
Be flexible on age cut-off for those going through this during the pandemic and experiencing delays		2	
Those undergoing fertility treatment should not be sharing waiting rooms with maternity patients		1	
Comment – recognise impact on mental health	2	1	
Consider those who are unable to go privately – from less deprived backgrounds and consider means testing	3		

Appendix 5 – Glossary of terms

Abandoned IVF cycle	Defined as an IVF cycle where an egg collection procedure has not been undertaken. Usually occurs due to a lack of response (where fewer than three mature follicles are present) or conversely if there has been an excessive response to ovarian stimulation and the patient is at risk of severe ovarian hyperstimulation syndrome (OHSS). May also be referred to as a 'cancelled cycle'.
Artificial insemination (AI)	AI is the introduction of sperm into cervix or uterine cavity. Intrauterine insemination (IUI) is a type of AI undertaken at a fertility clinic where sperm is filtered to produce a concentrated 'healthy' sample which is placed directly into the uterus. AI undertaken at home would normally be intra-cervical insemination (ICI).
Assisted conception treatment (ACT)	The collective name for treatments designed to lead to conception by means other than sexual intercourse. Includes: intrauterine insemination (IUI), in vitro fertilisation (IVF), intracytoplasmic sperm injection (ICSI) and donor insemination (DI).
Azoospermia	Where there are no sperm in the ejaculate.
Cryopreservation	The freezing and storage of embryos, sperm or eggs for future use in IVF treatment cycles.
Donor insemination (DI)	DI is a type of fertility treatment in which high quality donor sperm is injected directly into the womb (IUI) or cervix (ICI). DI is commonly used when either the male partner has no sperm or for lesbian couples/ single women.
Egg (oocyte) donation	The process by which a fertile woman donates her eggs to be used in the treatment of others.
Embryo transfer	The procedure in which one or more embryos are placed in the uterus.
Embryo transfer strategies	Defines the number of embryos that should be transferred in an embryo transfer procedure, depending on factors such as the age of the woman and the quality of the embryos.
Endometriosis	A condition where tissue similar to the lining of the womb starts to grow in other places, such as the ovaries and fallopian tubes.
Fertilisation	The union of an egg and sperm.
Fertility policies	CCGs are responsible for commissioning most fertility treatments; most therefore have policies in place specifying which interventions are funded and eligibility criteria for access to these. These policies typically explain when the CCG will fund fertility treatments for people experiencing infertility and assisted conception treatments for patients who require interventions for other reasons e.g. fertility preservation for patients due to undergo a gonadotoxic treatment.
Fertility preservation (FP)	Fertility preservation involves freezing eggs, sperm, embryos or reproductive tissue with the aim of having biological children in the future.
Fresh IVF cycle	Comprises an episode of ovarian stimulation and the transfer of embryos created that have not previously been frozen.
Frozen embryo transfer (FET)	Where an excess of embryos is available following a fresh cycle, these embryos may be frozen for future use. Once thawed, these embryos may be transferred to the patient as a 'frozen embryo transfer'. Also known as a 'frozen IVF cycle'.
Full IVF cycle	Defined by NICE as one episode of ovarian stimulation and the transfer of any resultant fresh and frozen embryo(s).
Gonadal dysgenesis	Abnormal development of a gonad (ovary or testicle).
Gonadotoxic treatment	Treatments that can cause infertility such as some chemotherapies.

Infertility	Infertility is the period of time people have been trying to get pregnant (conceive) without success after which formal investigation is justified and possibly treatment implemented.
In vitro fertilisation (IVF)	IVF involves ovarian stimulation and then collection of a woman's eggs. They are then fertilised with sperm in a lab. If fertilisation is successful, the embryo is allowed to develop for between two and six days and is then transferred back to the woman's womb to hopefully continue to a pregnancy. Ideally one embryo is transferred to minimise the risk of multiple pregnancy. In older women, or those with poor quality embryos, two may be transferred. It is best practice to freeze any remaining good quality embryos to use later on in a frozen embryo transfer if the first transfer is unsuccessful.
Intracytoplasmic sperm injection (ICSI)	IVF with ICSI treatment is similar to standard IVF. However, instead of mixing the sperm with the eggs and leaving them to fertilise in a dish, an embryologist will inject a single sperm into each mature egg. This maximises the chance of fertilisation as it bypasses any potential problems the sperm may have in penetrating the egg.
Intrauterine insemination (IUI)	IUI is a type of fertility treatment in which the best quality sperm are separated from sperm that are sluggish or non-motile. This sperm is then placed directly in the womb. This can either be performed with the woman's partner's sperm or donor sperm (known as donor insemination or DI). Sometimes ovarian stimulation is used in conjunction with IUI.
Male factor infertility	Problems with male fertility are related to sperm, sperm production and the reproductive tract.
Men/ male	Due to the nature of policies on assisted reproductive technologies, it is necessary to refer to the sex of patients on occasion. This document therefore refers to 'men' and 'male'. When these terms are used in this document, unless otherwise specified, this refers to sex defined by biological anatomy. It is acknowledged that this may not necessarily be the gender to which individual patients identify.
Natural cycle IVF	An IVF procedure in which one or more oocytes are collected from the ovaries during a spontaneous menstrual cycle without any drug use.
NICE	National Institute for Health and Care Excellence. NICE provide national guidance and advice to improve health and social care. NICE guidelines are evidence-based recommendations for health and care in England. Organisations commissioning and delivering services are expected to take the recommendations contained within NICE clinical guidelines into account when planning and delivering services. NICE has published a Clinical Guideline (CG 156) on fertility problems.
Oophorectomy	An operation to remove one or both ovaries.
Ovarian Hyper-Stimulation Syndrome (OHSS)	A condition in which the ovarian response to stimulation results in clinical problems, including abdominal distension, dehydration and potentially serious complications due to thrombosis and lung and kidney dysfunction. It is more likely in women who are excessively sensitive to medicines used for ovarian stimulation.
Ovarian reserve	A woman's fertility is related to the number of eggs remaining in her ovaries, referred to as 'ovarian reserve', which influences the chance of becoming pregnant.
Ovarian stimulation	Stimulation of the ovary to achieve growth and development of ovarian follicles with the aim of increasing the number of eggs released.
Ovarian tissue cryopreservation	Involves removing and freezing ovarian tissue from a girl or woman. At a later date, the ovarian tissue strips can be thawed and either re-implanted into the ovary, to allow them to try to conceive naturally, or the eggs can be retrieved and fertilised in vitro and the embryo implanted in the uterus.
Pathological	One that relates to medical conditions/ diseases (physical or psychological).

problem	
Pre-implantation genetic diagnosis	A technique used to identify inherited genetic defects in embryos created through IVF. Only embryos with a low genetic risk for the condition are then transferred back to the woman's uterus. Any resulting pregnancy should be unaffected by the condition for which the diagnosis is performed.
Premature ovarian failure	When a woman's periods stop before the age of 45. Also known as primary ovarian insufficiency or early menopause.
Rhesus (Rh) isoimmunisation	A condition where antibodies in a pregnant woman's blood destroy her baby's blood cells. Also known as rhesus disease.
Sperm donation	The process by which a fertile man donates his sperm to be used it the treatment of others. The HFEA regulates sperm donation undertaken at UK fertility clinics.
Sperm washing	Sperm washing is used to reduce the viral load (for example, of HIV) in prepared sperm to a very low or undetectable level. The washed sperm can then be transferred to the women using IUI or used to fertilise eggs in IVF or ICSI.
Supernumerary embryos	Un-transferred embryos created from a fresh IVF cycle.
Surgical sperm retrieval (SSR)	Surgical sperm retrieval means extracting sperm by a surgical procedure. Types of SSR include: percutaneous epididymal sperm aspiration (PESA), microsurgical epididymal sperm aspiration (MESA), testicular sperm aspiration (TESA), testicular sperm extraction (TESE) and microscope-assisted testicular sperm extraction (MicroTESE).
Surrogacy	Surrogacy is where a woman carries and gives birth to a baby for another person or couple. This may involve the eggs of the surrogate, the intended mother or a donor.
Unsuccessful cycle of IVF/ ICSI	Includes failure of fertilisation, failure of development of embryos and failure to conceive following transfer of embryos.
Women/ female	Due to the nature of policies on assisted reproductive technologies, it is necessaryto refer to the sex of patients on occasion. This document therefore refers to 'women' and 'female'. When these terms are used in this document, unless otherwise specified, this refers to sex defined by biological anatomy. It is acknowledged that this may not necessarily be the gender to which individual patients identify.