

NCL Fertility Policies Review

Engagement Report

August 2021



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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. North Central London has a population of approximately 1.44m residents, of whom an estimated 700 seek specialist fertility support each year.

Initial work began in September 2020, but elements of the project were paused as a result of the COVID-19 pandemic. Full work recommenced in April 2021 and is being done in two stages. The first stage was a Review, with the aim of producing a set of principles and recommendations to inform the development of the future single policy. No decisions on the future policy are being made in Review stage.

A key strand of the Review has been to seek the views of our residents, service users, voluntary and community (VCS) organisations, fertility groups and wider stakeholder audiences, both on our current fertility policies and also what the CCG should consider when developing the future policy. The engagement window for this work ran from 10 May to 9 July 2021; this document reports the findings from this engagement.

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 Review, 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 Review took place during the COVID-19 pandemic, which restricted engagement interactions to online and telephone methods. 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 interpreters at online events.

The numbers of people who took part in the engagement were relatively small, likely reflecting not only the challenges presented by the pandemic, but also the small numbers of people for whom this topic is relevant. Also, important to note, some stakeholders such as local Healthwatch and local VCS groups felt that it would be easier for residents and service users to provide feedback when the draft policy is available. We also received feedback from groups that residents and members had engagement 'fatigue' due to both local (NHS and Local Authorities) and national (central Government departments) undertaking a wide range of engagement through the pandemic period.

However, good and detailed qualitative insights and data were collected. The majority of people who engaged during the Review stage were past or present service users, and were well-informed about policies and treatments available. Every opportunity was given to hear views from across the board and the survey did draw a very small number of comments from people who thought that fertility treatment should not be available on the NHS.

As well as sharing views on current and future policy, many participants also shared information about their own experiences of accessing local services, which are detailed later in this report. NCL

CCG is committed to using these insights, working collaboratively with our Providers and residents, to improve local commissioning decisions and service provision.

The following summary of findings draws out the themes from engagement activity undertaken in respect of the Fertility Policies Review. The key headlines are categorised under policy, service experience and other points.

Policy:

- Development of a single policy is welcomed and there is strong feeling the future policy should follow NICE guidance / level up, not down (for example, 3 full cycles offered and Intrauterine Insemination (IUI) support offered across all boroughs)
- Outdated terminology is used in policies (more inclusive language needed for LGBTQ+ community)
- The new policy eligibility criteria should consider:
 - Previous child policy
 - Exclusions of young women with low AMH levels
 - BMI in some circumstances (e.g. for African women)
 - Clarity on donor assisted conception
- Clarity is needed around the policy, inclusion and exclusion criteria, permissible add-ins, and the treatment journey
- There should be equality of access for all, including same sex couples and single women
- New policy should consider including surrogacy
- Questions asked honouring commitments to treatment: will people on waiting list or part way through treatment be assured that they will get what they were expecting when policy changes?
- IUI should be offered for unexplained fertility before IVF, if women prefer

Service experience:

- Fertility treatment is considered a luxury, distress is not fully taken into account
- Ad hoc approach to male investigations. Male partners should be referred for tests beyond a sperm count earlier. There were long wait times for appointments, and referrals were only made when female partners were quite some way into the process
- The whole process needs streamlining, from referrals to waiting times, to reduce the delay
- Timescales and delays a common theme, including:
 - Going through primary care to get a referral
 - Timescales to qualify for referral (incl. referral time for male partners)
 - Waiting times to get appointments
 - Timescales between each stage of the fertility journey from referral to treatment
- Distress around operational elements – waiting rooms shared with maternity services (distressing when attending for fertility diagnostics, scans for miscarriage etc.)
- Access to psychological support should be available – mental health is a concern for people even prior to their first engagement with a GP, and throughout the whole process.
- Feedback was also received on mental health support (counselling) for women from Black, Asian and minority ethnic communities could be improved, related to pressures (from extended family) to conceive
- Impact of the pandemic: delays to access treatment, inability of partners to attend appointments

Other points:

- Improve training for GPs and others so they understand and communicate the new policy
- Is there ethnicity differences in fertility in women?

- A perceived lack of knowledge among healthcare professionals (including GPs) about the details of existing policies:
 - Patients need to educate GPs about policies, tests, and treatments.
 - GPs either did not know / misinterpreted details of their borough policy
- Risk that people from ethnic minority communities who live in NCL think the National Health Service is similar to the health provision in their country of origin, which means they could miss out on fertility support
- Requirement to have three miscarriages before investigations undertaken (distressing and delays timings for treatment)
- Fertility treatment is not a necessity and shouldn't be NHS funded. There are limited resources available for health care in general and huge backlogs for NHS treatment for life threatening and life changing conditions.

The views shared with the CCG through the engagement work as part of this Review were used to inform the development of principles and recommendations for the future policy, both of which can be found in the [Recommendation Report](#). Learnings from this phase will be used to develop and refine the Communications and Engagement Strategy for the next stage, commencing later this year.

It is important to note that a success of the engagement undertaken to date is the establishment of relationships with both local communities across NCL and colleagues at local NHS providers and local authorities who can assist us in promoting the draft single fertility policy.

2. Fertility Policies Review: Communications and Engagement Strategy Development and Oversight

The Fertility Policies Review engagement strategy was designed to meet statutory requirements and guidance, which derive from the following:

- NHS Act 2006 (amended) – s14Z2 (CCGs)
- NHS guidance: Planning, assuring and delivering service change for patients¹
- Local Authority (Public Health, Health & Wellbeing Boards and Health Scrutiny) Regulations 2013
- Equality Act 2010 – including impact on groups sharing protected characteristics s149 (Public Sector Equality Duty)
- NHS England guidance on engagement

Fertility Policies Review Steering Group

The Review of the Fertility Policies has been led by a Steering Group, which reports into the NCL CCG Governing Body via the NCL Strategy and Commissioning Committee. The Steering Group is chaired by the Clinical Responsible Officer (CRO) and comprises members including the Senior Responsible Officer (SRO), Governing Body Lay Member, clinical, specialist advisers and two Community Members.

Community Member roles

The two Community Members were recruited to the Steering Group to offer insight from two perspectives:

- a. Fertility Network UK nominated a member of their team to fulfil the Community Member 'expert' role; and
- b. One of the CCG's existing Community Members acted as the 'citizen' Community Member on the Steering Group.

These Members participated fully in the work of the Steering Group, contributing to Review plans particularly around communication and engagement activity. Community Members' participation has been particularly important in discussions around equity, equalities and accessibility considerations, and defining and considering ethical issues. They have provided vital, independent judgement on matters related to the Review.

Steering Group role in the development and oversight of the Communications and Engagement Strategy

The Steering Group contributed to the development of, and approved, the Communications and Engagement Strategy. During the engagement window of the Review stage, from 10 May – 9 July 2021, the Group was kept updated on the delivery of the engagement strategy.

An early findings report was brought to the May meeting of the Steering Group, and advice and guidance from the Group has been reflected in the iterative adaption of our approach and activity throughout the engagement period.

¹ Planning, assuring and delivering service change for patients, NHS England, March 2018
<https://www.england.nhs.uk/wp-content/uploads/2018/03/planning-assuring-delivering-service-change-v6-1.pdf>

The Steering Group agreed to ensure that when analysing and reporting on the engagement response:

- All substantive points be captured, so the final report is a comprehensive account of views;
- The most common themes are identified and highlighted;
- Summaries are focused on Review recommendations and considerations; and
- Comments which are out-of-scope of the Review are collected and receive an appropriate response.

Engagement objectives

The Communications and Engagement Strategy was agreed by the Steering Group and confirmed that the purpose of the engagement period was to develop a comprehensive understanding of the concerns and issues that our residents would like the CCG to address in the development of a single policy. The Strategy had four objectives:

1. To advertise and encourage participation, reaching individuals and groups with views and insights to inform the Review through development of core materials and targeted promotion to facilitate their response;
2. To provide information about the Review, keeping stakeholders and residents updated and to ensure that questions about the Review are answered as fully as possible and discussion is enabled with timely, accurate information;
3. To provide the opportunity for residents to contribute to the Review through easy, accessible channels; and
4. To gather and analyse engagement responses and inform the Review with focused summaries of comments on key questions.

Pre-engagement activity

A programme of pre-engagement activity took place from October 2020 and key stakeholders were involved in shaping the Communications and Engagement Strategy and also in 'road testing' and refining materials to ensure they were as accessible as possible.

A workshop, led by the Deputy Chair of NCL CCG's Governing Body, was held on 21 October 2020 to co-design the Communications and Engagement Strategy. This was attended by representatives of local Healthwatches, VCS and Fertility Network UK, the Steering Group Community Members, and members of the CCG team.

Views were sought on:

- The best channels to use to reach people
- What they thought the most effective engagement methods would be, and
- What questions and issues they thought people might raise
- Views on the engagement questions

The main feedback from the workshop, and the steps the CCG took to ensure the feedback received was reflected in the final engagement strategy, are set out in the table overleaf:

Workshop themes	CCG engagement strategy approach
The topic and policies are complex but materials need to be simple and easy to understand to facilitate engagement	<ul style="list-style-type: none"> - Core engagement materials shared with Healthwatches and Community Member representatives to check accessibility - Easy Read version of core information pack produce; translated versions offered - Policy summaries produced, including simple table outlining key variance between policies
The need to be clear on the scope of the Review, and for engagement questions to reflect the scope	<ul style="list-style-type: none"> - Core information pack included clear information on Review scope, plus detail on what is in the scope of current policies - Steering Group members underwent training on facilitating engagement to support feedback focused on the Review scope
Draft engagement questions were thought to be very broad and possibly difficult to answer – it was suggested that prompts should be expanded, and in-context information be strengthened	<ul style="list-style-type: none"> - Final engagement questions reduced in number - Prompts included with final survey questions, to encourage feedback related to Review Scope - Core engagement information (including event presentation) provided clear information on the Review scope
The likelihood of people raising issues out of the Review scope	<ul style="list-style-type: none"> - NCL CCG committed to capturing all feedback received (including not directly relevant to scope of Review) and exploring how this can be used to improve service provision and experience (outside of the policy development work)
Importance of reaching reach as many audiences as possible, including BAME communities and LGBT+ communities, and to be mindful of cultural sensitivities	<ul style="list-style-type: none"> - CCG contacted 75 community organisations, including BAME, LGBT+ and wider communities in the pre-engagement stage, to seek early input on our proposed approach and current policies, and answer questions on the proposed Review
Social and digital media will be important channels of communication, but a variety of methods will be needed to be inclusive	<ul style="list-style-type: none"> - The CCG build a range of engagement methodologies – public meetings, focus groups, interviews, online survey. - Promotional communications indicated that one to one telephone support to complete the survey was available - Interpreting services were made available

Further pre-engagement activity comprised:

- Informal discussion with the NCL Joint Health Overview and Scrutiny Committee (JHOSC) Chair;
- A mapping exercise to identify priority audiences for Steering Group agreement;

- Developing a database of 75 key community and service user organisations, which included 38 groups representing protected characteristics;
- Linking in with the communications teams at the Trusts commissioned by NCL CCG to provide fertility services, to secure support in promoting the Review through their channels; and
- Running training sessions for Steering Group members who would be facilitating engagement activity.

Ahead of the start of the engagement window for the Fertility Policies Review, we wrote to a core list of 75 key stakeholders across North Central London offering the opportunity to discuss our approach and seek their early views. Responses received in the pre-engagement period were logged, and where relevant, used to inform our engagement approaches.

Engagement questions

Two broad, open-ended questions were developed as part of the pre-engagement work, with prompts to steer respondents' thinking appropriately to their interest but clustered around similar themes. The two questions were available as an online survey (via our website) and were also used as the basis for discussion in all other engagement activities such as workshops and online drop-in sessions.

The decision to frame the questions as open-ended was intended to invite a richness of response to guide not only the recommendations put forward to the second stage of work, but also to allow respondents the opportunity to reflect their own personal experiences.

Q1. What are your views on the current fertility policies?	Q2. What should we consider when developing the new fertility policy?
<p>Prompts:</p> <p>In providing feedback on this question you may want to consider:</p> <ul style="list-style-type: none"> • The eligibility criteria set out in (any of) the current policies • The treatments offered under (any of) the current policies • Any of the other services covered by the policies 	<p>Prompts:</p> <p>In providing feedback on this question you may want to consider:</p> <ul style="list-style-type: none"> • The eligibility criteria the new policy should or should not include • The range of treatments/interventions that should or should not be included • What you think we could improve when we develop the new policy <p>We would also welcome your views on:</p> <ul style="list-style-type: none"> • Access to fertility treatments for North Central London patients • Availability of helpful, easy to understand information • How the CCG should involve local people in developing the new policy <p>You may also want to share any experience of being referred/accessing fertility treatment under the NHS</p>

Core materials

- The core materials developed for engagement during the Review phase comprised:
Review questionnaire (see questions in the above table) hosted on the NCL CCG website, available to complete online, or to download/print if requested (Freepost return available) and distributed to key stakeholder database. Freepost return available.
- Patient information leaflet - incorporating questionnaire for download, and featuring key information to help respond to the questionnaire.
- An Easy Read version of the patient information leaflet
- Presentation for use at events – providing key information on fertility services, the five current policies, the scope of the Review and the engagement questions
- Comparison chart to explain the key differences between the five current policies
- Public frequently asked questions document
- Fertility Policies Review section on NCL CCG website – hosting all relevant information and materials throughout the Review period
- Stakeholder engagement materials – letters sent at key point pre- and during the engagement to encourage participation
- Spokesperson briefing materials to assist the nominated Steering Group representatives in effective facilitation of focus groups and online drop-in sessions, and to support uniform capture of insights.

3. Engagement methodology and activity

Breadth of engagement channels, forums and activity outline

The pre-engagement work informed the development of the Communications and Engagement Strategy. To ensure that the Review heard from a wide range of perspectives, our engagement used a variety of channels to maximise accessibility and reach. Our 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.

Core engagement activity

NCL CCG was committed to being flexible in how we heard from residents, service users and groups, and welcomed 1:1 conversations as well as the opportunity to attend existing events and meetings to discuss the Review. Written comments were welcomed and processed through a single document management system and a consistent analysis framework. However, the core engagement methods implemented by the CCG were:

Review Questionnaire

- Online version hosted on our website
- 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 Next Door (online neighbourhood network) with close to 9,000 impressions across North Central London resident online 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 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 Review 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:

- Three open-access online events were run 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 service user focus group, supported by Fertility Network UK
- A resident focus group with LGBT men
- A resident focus group, hosted in collaboration with the Enfield Racial Equality Council, which particularly welcomed people from local ethnic minority communities and those with lived experience from across the five NCL boroughs
- A resident focus group held with residents whose country of origin was not the UK

- Outreach via fertility group social media channels, including a pre-recorded Instagram Live event with The LGBT Mummies Tribe, which had over 350 views
- A pre-recorded question and answer session with Dr John McGrath (Clinical Responsible Officer) and Penny Mitchell (Programme Director), which was shared on the CCG's YouTube channel and via social media platforms in collaboration with The LGBT Mummies Tribe
- In-depth interviews held with residents from local BAME and LGBT communities

Wider stakeholder-focused activity:

- 1:1 briefings for key stakeholders and representative organisations
- Meetings with local organisations, including online groups, discussion sessions with groups
- In-depth interviews conducted with individuals with protected characteristics
- Attending/presenting at meetings organised by others, such as Healthwatch and local community groups, VCS organisations, PPG network meetings and local authorities
- Information shared with our communications counterparts in local authorities and Trusts

General Practice-focused activity

- Presentation by CRO and Programme Director to webinar for all NCL Governing Body GPs and clinical leads. This webinar is held weekly and chaired by the Chair of the CCG's Governing Body.
- Presentations to Borough-based GP Forums in Barnet and Islington

During the pre-engagement phase seventy eight organisations were contacted and invited to take part in the Review, as well as a wide range of stakeholders.

During the engagement phase:

- 52 people completed the survey
- 44 people were involved in group discussions, public online sessions and interviews
- 350+ people viewing a Mummies' Tribe Instagram Q&A session
- From the FPR public website you can see the number of times documents were downloaded by visitors to the webpage.
 - NCL Fertility Review Questionnaire – 103 downloads
 - Patient Leaflet – 131 downloads
 - NCL FPR Variations slide deck – 149 downloads
 - Barnet Fertility Policy – 111 downloads
 - Camden Fertility Policy – 106 downloads
 - Enfield Fertility Policy – 89 downloads
 - Haringey Fertility Policy – 113 downloads
 - Islington Fertility Policy – 84 downloads
 - NCL CCG Fertility Policies Review FAQs – 104 downloads
 - North Central London Fertility Policies Review - Easy Read Leaflet – 122 downloads
- 31 Tweets were sent from the NCL CCG's account which had 27,954 impressions on local stakeholder and resident twitter accounts raising awareness of the Fertility Policies Review.

Although overall participation numbers are relatively small two things should be considered:

- Specialist fertility services are accessed by around 700 NCL residents each year, and so numbers are likely to reflect the small numbers of people for whom this topic is relevant.
- The engagement period for the Review stage took place during the COVID-19 restrictions of late 2020 and early 2021.

To maximise involvement, the Fertility Review team adapted their approach through the engagement period based on learnings and feedback gathered as we progressed. The learnings from undertaking this engagement will be used to inform our Communications and Engagement Strategy and approaches for the second stage, seeking views on the draft future fertility policy. Further detail on this is provided later in the report.

Throughout the nine week engagement period the CCG promoted the opportunities to participate through all our public and stakeholder-facing channels, and would like to thank all partners for their support in also helping to promote the Review.

The attached appendices list the following information:

- Appendix 1 Engagement events and meetings
- Appendix 3 Engagement Log
- Appendix 2 Survey demographic data
- Appendix 4 Written responses received from survey responses

4. Main themes from engagement

This section reports on the main themes from the engagement – received via survey responses, public meetings, and community and wider stakeholder engagement. Feedback has been split into that which specifically addresses the review of policies, and that which is more experiential and which the CCG will consider when making commissioning decisions and to improve care provision.

There was a general consistency of views across all the engagement sessions and survey responses. Overall the most frequently mentioned aspects were:

- Almost all respondents felt that the new policy should “level up” to the highest provision currently available across NCL for each area not down. For example, offering three cycles of IVF (the current greatest level of provision available across NCL)
- Eligibility criteria should be reconsidered in the future policy, in order to remove current inequalities. For example, some individuals having to self-fund Intrauterine Insemination (IUI)
- Cultural and faith differences should be considered
- The fertility pathway needs streamlining – from referrals to waiting times – in order to cut delays
- The policy, pathways and treatment information should be clear and transparent, and be given to service users at their first GP appointment to discuss fertility issues
- There should be improved training for all healthcare professionals working in fertility environments. Frequently heard experiences from both event participants and survey respondents included including lack of knowledge from their healthcare professionals on what the policy is, what inclusion/exclusion criteria are, and what pathways are available.
- A number of respondents reported experiencing a lack of empathy from staff across all settings and felt that training on softer skills such as empathy and compassion for service users is needed.

These issues are discussed below under the themes of participants’ views on: current policies; what should be considered in developing the new policy; policy implementation; clinical education and training; and service provision and service users’ experiences.

Views on current policies

A significant proportion of the respondents were current or past service users or had connections to people who were. The differences in the number of cycles of IVF funded under each of the individual policies was seen as the biggest and most problematic disparity between the five legacy policies. A commonly heard view was that the disparity between the different Boroughs’ policies resulted in a ‘postcode lottery’.

Service users described having to find things out for themselves, and a common theme was that their GPs had not known what policies in their Borough were, or had wrongly interpreted them. One person said that her GP had eventually referred her to a hospital which did not do fertility treatment, which caused delays whilst she got a further referral to an appropriate hospital.

We heard a number of views that the current policies could be improved in terms of equality of access to services. A survey participant from Camden said:

“6 cycles of IUI can cost up to £30,000 in a clinical setting. NICE does not stipulate insemination must happen in a clinical setting... as far as we [the respondent and her wife] are concerned, this policy stance amounts to unlawful discrimination under the Equality Act 2010 on the grounds of our sexuality.”

Further, the BMI requirements were felt to be discriminatory for women from some communities; this was particularly mentioned by Black African women.

A small minority (four of the 52 survey responses) suggested that fertility treatment should not be available on the NHS as money would be better used elsewhere. All other responses spoke positively about the need for fertility treatment to be available and that the criteria for inclusion should ensure that there is equality of access.

Generally, people felt that there was currently a lack of clarity for service users. One survey respondent from Camden said:

“The process is not clear and the bouncing between gynaecology, urology, andrology, fertility and general practice causes significant stress, confusion and a feeling of helplessness for patients.”

Time and delays were discussed in detail, as time was of the essence for most women seeking fertility treatment; people said that they felt each delay reduced their chances of conceiving. For heterosexual couples, one source of delay identified was in investigating male infertility, and there was a strong and often-heard view that testing and treatment for male partners should run concurrently with testing and treatment for female partners, so that less time was lost.

Participants said that current policies did not pay heed to the psychological needs of service users, and that the process itself caused stress and anguish

A survey participant from Barnet said:

“Firstly you need to consider how fragile people are when they aren’t able to do what we perceive to be our reason to exist. We are not a number. We are people and we are scared. When we ask for help to have a baby we are already a little bit broken, but we are also very brave and very determined and many of us already know in our hearts that asking for help is the start of a very lonely and painful journey that may never give us the baby we crave. Time is not on our side, diagnosis and decisions about treatment needs to be made quickly.”

One person in the service user focus group said of the three miscarriage rule:

“...do you really have to wait until you’ve had three miscarriages before tests are done? This is beyond cruel and should be revised.”

[Views on what should be considered when developing a new policy](#)

There was agreement that a single policy across NCL would be beneficial, removing variations between boroughs. People expressed strong views that the new policy should “level up”, not down, for example, that the three IVF cycles currently offered in Camden should be adopted across NCL.

A high number of survey respondents felt that a new policy should reflect NICE guidelines in full. This view was echoed by Healthwatch Islington during both the May meeting of the Engagement Advisory Board and also at a briefing held by the CCG team for our five Healthwatches. At the former, they explained that they felt that NICE guidance in this area should play a key part in developing the policy, and at the latter they commented:

“I think a consistency of approach across the boroughs is key – would like all to be in align with the NICE guidance. If not – it is your role to make a good enough case for why this is not a good enough starting point.”

Service users in particular viewed the development of a single policy as an opportunity to improve the policy, not just by ensuring parity but also by:

- developing a clearer policy;
- considering some elements of the current policies thought to be unfair or discriminatory;
- including elements currently missing from policies, such as psychological support.

It was felt that the new policy was an opportunity to ensure that there was equality of access to fertility treatments, for example, for same sex female couples and single women. Further, it was thought that the following aspects of the policy should be reassessed:

- IUI should be available to same sex female couples and single women
- Treatment should be offered if IUI in a non-clinical setting has been tried
- Donor assisted conception should be available for all
- The previous child criterion should be removed
- The BMI criterion should be flexible to take into account ethnic and cultural differences
- Investigate for fertility problems earlier than the current ‘three miscarriages’ requirement

There was a suggestion from some LGBT+ groups that more inclusive language should be used in the new policy as the term ‘same sex female couples’ was unsuitable.

Service users were keen that the new policy should be written in a way that is easy for patients to understand and that it should provide a clear pathway to signpost both clinicians and patients.

Patients thought that the new policy should consider ways to ensure the pathway is smoother and faster with fewer delays and asked whether some of these could even be considered ahead of the new policy.

Views on service provision and service users’ experiences

Many service users, past and present, said that they felt that psychological support should be offered; there was consensus that patients who had miscarried or whose treatments had failed should have support readily available, but people also said that the whole process was difficult and that there should be access to psychological services throughout.

A respondent from a voluntary organisation said:

“We would like to see the devastating emotional impact of fertility problems taken into account, and infertility recognised as a disease as classified by the WHO.”

A couple attending the service users’ focus group said that they had found the whole process of seeking help, having tests and then treatments to be extremely stressful – and that this was worse when they suffered miscarriages. They had searched for what psychological help might be available to them, and found that their treating hospital did offer this service, but that no-one had told them about it or suggested psychological services to them. They felt strongly that not only should clear information about currently available treatments be available to service users, but that the new policy should both put in place psychological support and have clear signposting from the earliest stages.

Service users also talked about distressing experiences when maternity and fertility services shared provision; for example, fertility patients waiting for a scan to confirm miscarriages had to share a waiting room with women having pregnancy progress scans. Respondents asked why the clinics could not be split so that this did not happen.

Whilst people acknowledged that during the pandemic services had to be delivered as safely as possible, some had found it hard to have partners excluded from tests and scans. More broadly, there was a call for partners to be made very much a part of the process. One man in the service user focus group said:

“I’m just shut out of everything. I’m left in the waiting room, and I know that’s to do with COVID, but some of these moments are, especially with miscarriage, are the hardest moments of our lives together, and I’m sitting outside the hospital in the snow waiting to find out whether or not we are miscarrying.”

The man’s partner said:

“He’s not been able to come to any of our appointments, so every time we’ve had a miscarriage I’ve had to find out by myself... it needs to be treated as a couple, it can’t just be the woman being treated as the patient, it needs to be a combined approach.”

It was common for service users to talk about delays in the fertility pathways, describing delays happened at all points, including referral to services, waiting for a consultation, time between treatments, and timing of treatments. Women with male partners said that male infertility was investigated at a basic level only initially, and that female infertility was then assumed to be the problem. Tests and treatments were often long underway before more detailed exploration of the male partner’s fertility was undertaken.

Referral times for male infertility were cited as long; people reported a wait of up to a year for a consultation, adding considerable delay to the process. One woman said that earlier investigation into her male partner’s fertility would have revealed that a simple operation would have solved the problem, however, she had already undergone unsuccessful treatments and she was now on the cusp of the age limit.

One specific point of delay resulted from clinics not offering IUI at weekends; patients said that this could result in at least a month’s delay and asked why clinics did not run seven days a week.

When asked where improvements could be made, service users identified the following areas:

- GPs could be better informed about policies, referral routes and treatments
- Patients could be given more information about support groups, policies, psychological support, how long the process might take and an outline of what treatment routes there might be (for example, if tests are needed, on which day of a cycle should they be done)
- There could be clarity about things such as permissible treatment ‘add-ons’, when ‘the clock starts’ for two years of trying to conceive and what the three miscarriage rule means
- The process should be smoother and with fewer delays
- Staff training on the likely stress people experience in accessing services may help to mitigate the lack of empathy some patients experienced
- Investigate male partner infertility earlier in order to reduce delays
- Take a combined approach to a heterosexual couple’s fertility and treatment.

Views relating to policy implementation

Service users often reported that information about fertility policies, investigations and treatments were scarce, and they had had to undertake their own research. Generally, respondents felt there was a lack of clarity and that having information about support groups, policies and processes would improve their experience. A survey respondent from Barnet said:

“Clarity in the provisions is key. Infertility causes a huge amount of grief and fear. This is exacerbated by a fog of differing information. I remember the sheer panic of time ‘running out’ and being so unsure what to do for the best... Clear and accessible information upfront is vital.”

People called very strongly for a clear and transparent guide, which would be available to patients from their first visit to a GP, explaining what the policy is, what timelines are likely to be, and what add-ons can be used. Good information at the time of referral would improve patients’ experiences.

As referenced earlier, some service users said their GPs were not well informed about policies, procedures or treatments, and there was a call for this to be rectified, by GP training or a ‘one stop shop’ for GPs to refer to.

There was also a suggestion from service users that a ‘patient navigator’ would help peoples’ journey through a complex and emotional process; they said that having someone with an overview of the policy and how it related to them personally would be very helpful.

Current service users asked how their treatment might be affected if/when the policies change. There was a concern that if there was any “levelling down” they might not get the treatment they expected. People asked for clarity on this as a matter of urgency, so that they would know what to expect.

In a focus group with three British Asian women, feedback was shared that the CCG must consider ethnicity data related to service use, in order to understand who will benefit from the future single policy. They recommended information be made available in different languages and formats, promoted through local community groups, to ensure a wider reach across NCL. The group discussed the possible taboos about fertility in some communities, and thought that information about NHS treatments might encourage them to seek help.

One participant fed back:

...“some people don’t know about the treatments available to them and that there is a stigma around fertility within some cultures.”

“The problems are seen to be with the women... [they worry] that their husband will take a younger woman – the clock is ticking for woman to have a baby.”

“...in allowing people to understand what choices may need to be made further down the line in regards to potential success/failure of treatment undertaken”.

We received feedback that inequalities in terms of awareness of services mean some people may leave seeking help too late, and eligibility criteria, such as age, smoking, and BMI, could then reduce access and their chances of successful fertility treatment if required.

Views relating to clinical education and training

As mentioned, some service users found that their GPs were not well informed about fertility policies, tests or treatments. One woman described having been referred for treatment to a hospital which did not offer fertility treatment, which caused distress and delay. There was a strong feeling that GPs should be better trained and informed about the new fertility policy, and the processes for making referrals.

A woman talking about the problems of women who did not speak English, told the following story:

“Fertility is not always the women’s fault as I know of an occasion when the man was the problem – they both went for tests in the NHS – she couldn’t read or write English – he told her she was the problem... [later] someone read the letter to her and told her that he had the problem. Men are usually better educated.”

Healthcare providers should take into consideration whether both partners can understand the information they are given. Further, there should be training for healthcare providers about cultural and religious requirements; one participant in a focus group said that:

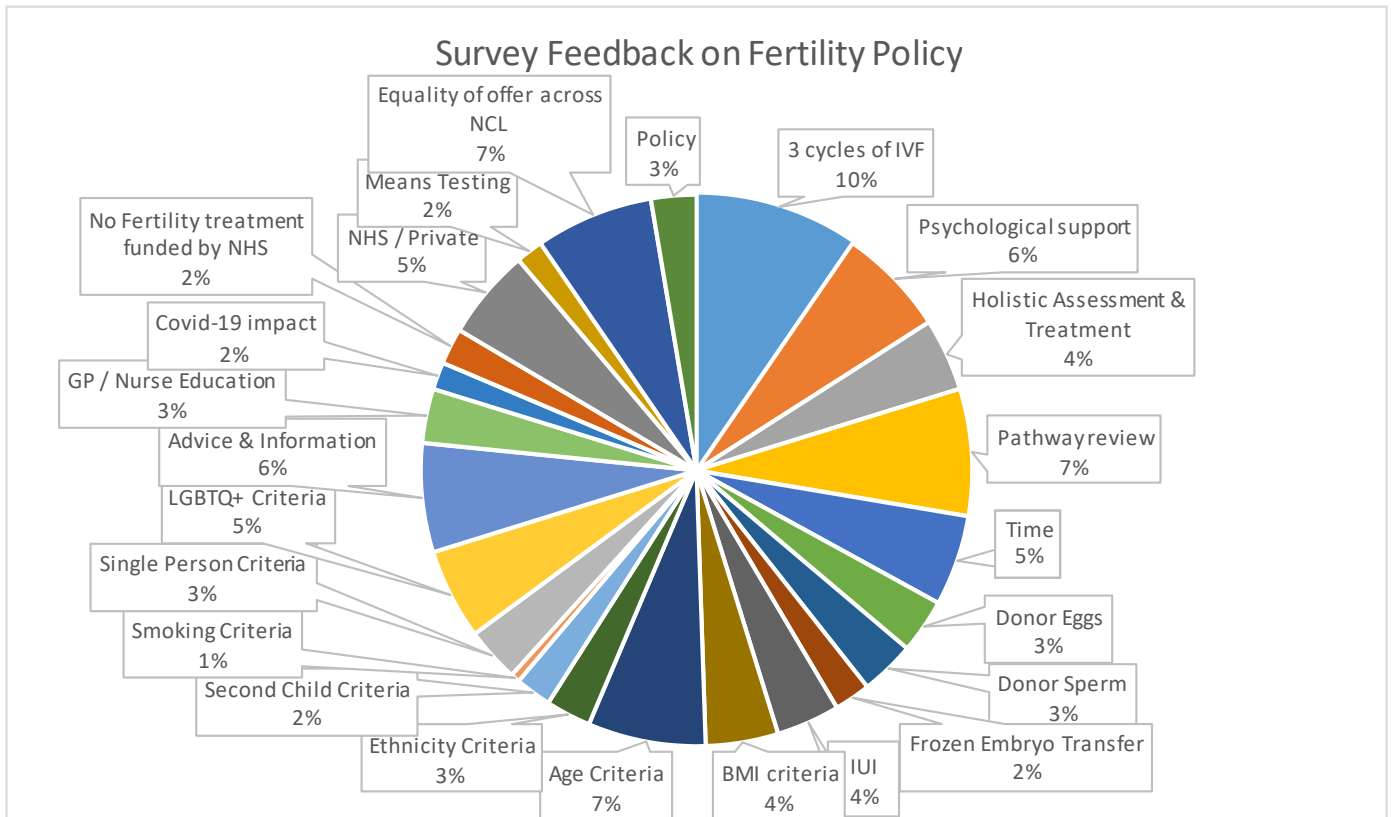
“In Islam fertility treatment is allowed as long as it’s your husband’s sperm. Must be both from husband and wife”

This was not investigated to see if it is for all forms of Islam, but there should be awareness of cultural and religious differences.

Some people found that staff lacked empathy, even in specialist services. One woman reported that she was crying whilst waiting for, and having, a scan to confirm a miscarriage and the only person who showed empathy was the receptionist. People felt that there could be more training for staff coming into contact with patients undergoing fertility tests and treatments so that they understood the emotional needs of patients.

It is difficult to draw conclusions about equality, diversity and inclusion from these data, as the numbers of people taking part from protected characteristic groups were small. Some findings should be read with caution in terms of representation of minority ethnic groups and LGBT+ communities. While the insight we obtained from talking to representatives was invaluable, we cannot assume that two or three people from a particular community represent the views of all within that community. The CCG will undertake an Equalities Impact Assessment in the second phase of work in developing the future policy.

Survey feedback: There was a general consistency of views across all the engagement sessions and survey responses. In relation to the survey feedback the most frequently mentioned aspects were:



The information below highlights the key messages from the survey feedback which was shown in Fig 1. Please note that you can go to Appendix 4 for more in-depth information related to the written feedback given under the headlines below.

3 cycles of IVF

- From the feedback received the importance of 3 full cycles of IVF being available, and NICE guidance on what constitutes a full cycle being followed, was highlighted.

Psychological support

- From the feedback received the need for mental health support for people going through the fertility treatment pathways was highlighted.

Holistic Assessment & Treatment

- From the feedback received the importance of people being treated as a whole person was highlighted with more seamless pathways between services required.

Pathway review

- From the feedback received people felt that the pathway could be streamlined to respond to the urgency of people's need to conceive was highlighted.

Time

- From the feedback received the delays in time while going through the pathways were highlighted as an area of concern.

Donor Eggs / Donor Sperm / IUI

- From the feedback received issues highlighted that NICE does not stipulate insemination must happen in a clinical setting to donor assisted routes should be factored into the standardised policy.

Frozen Embryo Transfer (FET)

- From the feedback received the need to standardise the number of transfers offered was highlighted, and a question raised about the whether it is ethical to offer NHS-funded treatment to create an embryo and then say it can only be stored and transferred if a patient has the funds to pay for this privately.

Advice & Information

- From the feedback received the need for clear and accurate information was highlighted for people going through the pathways with one comment highlighting the need for a patient leaflet summarising the fertility pathway within NCL at the time of referral by their GP.

GP / Nurse Education

- From the feedback received training for Clinical Nurse Specialists and GPs was highlighted to allow patients to have a better understanding of the pathways ahead.

COVID-19

- From the comment received concerns about the delays in progressing through the pathway due to COVID were highlighted as being unacceptable.

Eligibility Criteria

- From a comment received more flexibility for BMI in older women was highlighted if they do not need to lose weight to improve PCO. The respondent felt that the BMI criteria effectively excluded a number of patients who are not able to lose the weight in the time needed to qualify under the age criteria.

Age Criteria

- From a comment received more flexibility of services offered for older women between 40-45 was highlighted to be given the same opportunities as younger women. The respondent also touched upon people trying to start families at an older age.

Ethnicity Criteria

- From the feedback received BMI was highlighted as a problem as it was not a good indicator of health for women from ethnic minorities and clinicians should use more flexibility in supporting women from these communities with high BMI. A comment was also received which suggested that a clinical said your people have a lot of children. The patient explained to them that she had none.

Second Child Criteria

- From the feedback received more flexibility was highlighted in cases where one partner has a child and the other does not.

Smoking Criteria

- From a comment received smoking criteria (inc. age and BMI) was highlighted as fair.

Single Person Criteria

- From feedback received a comment highlighted that single women should be able to have fertility support (incl. IUI).

LGBTQ+ Criteria

- From feedback received concerns were raised about same sex couples not getting the same access to fertility support as heterosexual couples across NCL. Concerns were raised that some of the current policies may be discriminatory.

No Fertility treatment funded by NHS

- From the feedback received two comments were received highlighting that fertility treatment should not be provided by the NHS.

Private Provision

- Feedback received highlighted the potential exploitation of vulnerable people by the private market (e.g. online market for Clomid and provision of non-evidence based practices).

Means Testing

- Feedback received highlighted the need for more flexibility being given for people who can't afford to go privately.

Equality of offer across NCL

- Feedback received highlighted that it would be devastating if the IVF offered was changed to the lowest existing offer, to level up not down and confusion on why there is currently a postcode lottery in NCL when it comes to accessing fertility treatments.

Policy

- Feedback received highlighted that fertility support services should run at weekends and a comment also suggested that engagement during phase one should have held open town hall public meetings.

5. Use of engagement results to inform policy recommendations

The insights we received throughout the nine week engagement period were logged and reported to the Review Steering Group, with an early findings report presented and carefully considered by the Group in May. This enabled the Steering Group to consider ways to tailor the communications and engagement work during the second half of the Review period, to further explore emerging themes and issues.

Throughout the Review period, the insights generated through the public, patient and stakeholder engagement activity were viewed by the Steering Group alongside the wider Review work of clinical and specialist engagement, research and analysis activity. This was to ensure all data and feedback gathered by the CCG could be considered in the round, to inform work to develop principles and recommendations for the future policy development. Issues around equity and equality were given careful consideration across all aspects of the Review work.

The final results of the public, patient and stakeholder engagement activity were collated and analysed in July 2021. A summary of findings from the full engagement programme was brought for discussion to the Fertility Policies Review Steering Group, as well as the Review Clinical Reference Group and a CCG Governing Body workshop, across July. The findings were reviewed alongside the report setting out draft set of principles and review recommendations, to ensure Steering Group members were assured that engagement insights had been considered and reflected in these.

In addition to capturing and reporting all engagement insights relevant to the current and future policy, the CCG also logged and considered the breadth of views shared by participants policy implementation; clinical education and training; and service provision and service users' experiences.

The full results from our engagement work were then used to inform the CCG's development of the final set of principles and recommendations for the future policy. These can be found in the [Recommendation Report](#).

Appendix 1: Engagement events and meetings

Event / Meeting	Number of participants	Details & headline themes
Service user focus group	9	<p><u>Details</u></p> <ul style="list-style-type: none"> ▪ 5 female ▪ 2 female/male couples ▪ All participants were recruited by Fertility Network UK <p><u>Headlines</u></p> <ul style="list-style-type: none"> ▪ 3 full cycles should be offered across all boroughs ▪ Ovarian reserve (strange interpretation of NICE guidance) ▪ The time it takes to get through the system (a lot of wasted time) ▪ GP's need to be more of an expert on the patient pathway. ▪ Need more medical advice – not getting it which means researching yourself and then having to tell the doctor what to test. ▪ NHS should promote support groups – social prescribing. ▪ Every new path is just a new obstacle. ▪ Patient navigators/volunteers is needed to help people through pathways. ▪ Mental health support should be commissioned within the policy. ▪ Services should be available over the weekend. ▪ Needs to be more flexibility in relation to eligibility criteria.
Service user interviews	2	<p><u>Details</u></p> <ul style="list-style-type: none"> ▪ 2 female ▪ Telephone interviews with respondents who could not attend the focus group <p><u>Headlines</u></p> <ul style="list-style-type: none"> ▪ No choice of hospital referral ▪ 1 cycle doesn't allow for trying things – learn from first cycle ▪ Alternative therapies and counselling needed because pathways are so stressful ▪ Framed as a woman's problem - looking at the man's health should also be a priority ▪ "It's a rich person's game trying to have children if you have problems". ▪ What happens if a couple have different GPs – tied to woman's GP even if male factor involved

The LGBT Mummies Tribe Instagram recording	Viewed by 350+	<p><u>Details</u></p> <ul style="list-style-type: none"> ▪ A recorded Q&A session with questions gathered and posed by a Mummies' Tribe representative to Dr John McGrath and Penny Mitchell <p><u>Questions received from The LGBT Mummies Tribe Community</u></p> <ul style="list-style-type: none"> ▪ Is the CCG looking to make all CCG's provide equal access to funding for LGBT+ couples? ▪ Why do certain boroughs not provide funding? ▪ I have a child from a previous marriage and am with my wife - would we have access to funding? ▪ How long will it take for the new policy to be confirmed and when it does then be available? ▪ Will you make it equal for heterosexual and LGBT+ people - is this the aim of a new policy?
Public drop in meeting No 1	2	<p><u>Details</u></p> <ul style="list-style-type: none"> ▪ 2 female ▪ 1 current service user ▪ 1 Dr from India interested in the subject <p><u>Headlines</u></p> <ul style="list-style-type: none"> ▪ COVID – really hard re. waiting and eligibility ▪ Many need more than 3 cycles – need to have more than one chance ▪ Age criteria is very difficult for women ▪ Communications with women needs to be better throughout the pathway. ▪ Number of IVF cycles vary – need to come to common consensus
Public drop in meeting No 2	6	<p><u>Details</u></p> <ul style="list-style-type: none"> ▪ 5 women – one of whom identified as lesbian ▪ 1 male <p><u>Headlines</u></p> <ul style="list-style-type: none"> ▪ Protocols about conditions to enter treatment e.g. waiting for a year. Might this mean other conditions get worse or not picked up? Can access to investigation get sharper? ▪ Speaking as someone in same sex couple (age 36), looking at guidance it seems discriminatory. As same-sex couple we have to go through c£7K IUI before eligible

		<p>for NHS IVF. Huge financial cost – from personal perspective and from LGBT community – looks discriminatory</p> <ul style="list-style-type: none"> ▪ NICE Guidance is 3 cycles – wouldn't want Review to lead to reduction in Camden ▪ How do we avoid "race to the bottom"? ▪ Fertility considered a luxury – level of distress not taken on board fully for the people it affects. ▪ Given likely level of failure is it good value to offer just one cycle? Is there an alternative offered if the first is not successful?
Public drop in meeting No 3	6	<p>Details</p> <ul style="list-style-type: none"> ▪ 6 female <p>Headline themes</p> <ul style="list-style-type: none"> ▪ What does it mean for Islington funding "up to" 2 cycles – we had been told it was 2 cycles, but after 1 unsuccessful cycle, attended appointment which we were thought was to plan the second cycle - but told not planning second cycle but end of journey. The policy is unclear which has a big effect on people because of this. ▪ Investigations into male infertility needs to be looked at quicker – it is not always a women's problem. ▪ Emotional wellbeing is a big part of this and clinicians can be insensitive ▪ Homerton told us that Asian ethnicity means 6 years earlier fertility clock than Caucasians – if that is the case, the policy should involve a different approach ▪ Mental health aspect - went private with father's inheritance – this included counselling. Would have been helpful if available for NHS cycle. ▪ Pathway should include all tests as early as possible ▪ Could the NHS do egg-sharing programmes like private clinics do
African Health Forum member interview	1	<p>Details</p> <ul style="list-style-type: none"> ▪ Black African female, Christian, Heterosexual, 45-54 ▪ Not a service user <p>Headlines</p> <ul style="list-style-type: none"> ▪ IVF should be generous across all the boroughs and all residents should have IUI for same sex couples should be more generous. If there was a single policy – they would like to see all treatments are available are applied to the people that would like to have treatment.

		<ul style="list-style-type: none"> ▪ Women are going abroad to get treatment as they are not aware of the fertility support in the UK. ▪ Some African nationals living in NCL think that the health service is similar to the service in their country of origin which means they miss out on fertility support. ▪ When the single policy has been passed it should be made public so that people are aware of it and can get support on the NHS. ▪ Interviewee knows of people who could have had treatment but didn't know to ask.
Hopscotch Asian Women's group interview	1	<p><u>Details</u></p> <ul style="list-style-type: none"> ▪ Asian female, Zoroastrian, bi-sexual, 45-54 <p><u>Headlines</u></p> <ul style="list-style-type: none"> ▪ IVF inequality would lead to a sense of frustration if you lived in a neighbourhood borough a few streets away and you don't have access to that service. What hit me was the lack of services in Camden and elsewhere for same sex couples. ▪ Enfield and Haringey – we know that Camden has high population of same sex couples / don't know the comparison with the other boroughs (some have an option that the others don't have). Where is the highest need – Camden is a safest place for same sex couples to live and would have thought provision would have been better. ▪ Again the inequality in number of IVF treatments across the boroughs shows a huge disparity in that depending on where you live – one has a much greater chance of having a baby. ▪ Mental Health - thinking about the black minorities ethnic communities – can be such an extreme pressure on the family – not to have the same cycles can have a big effect on men and women and in these communities - women can be seen as the sole person responsible for bringing a baby into the world. ▪ We know the language around mental health is complex for BAME communities – there is shame and accompanying barriers when talking about mental health. When asked to rate your mental health an accurate picture might not be gained ▪ All clinicians need to be able to explain it very clearly. When giving information to a patient doesn't mean that clinicians can read a complex policy.
Enfield LGBT Network interview	1	<p><u>Details</u></p> <ul style="list-style-type: none"> ▪ White British male, Christian, gay, 55-64 <p><u>Headlines</u></p>

		<ul style="list-style-type: none"> ▪ In relation to the Enfield policy eligibility criteria – I agreed with most of it. If you don't start IVF until you are 40 and it takes two goes it could be a long time. Could be too late to start the process. ▪ I didn't read the other policies but the single policy could look like the Enfield policy – seems to be very balanced and fair – needs to be one policy across the five boroughs. It would be ideal if it was across the whole of London. ▪ The policy didn't cover surrogacy very much which it could have – one of our members went down this route but they didn't think it should be funded by the NHS – some people may have a different view. ▪ Training for staff - If you are offering these treatments for the LGBT community and same sex couples – staff need appropriate treatment for the client group in how to communicate and address the different client groups. Staff training is a key issue. It is about language and accepting that the partner happens to be the same sex and is as important as the husband would be. The relationship is as real and genuine as a traditional married couple would be. ▪ This policy needs to be equal across the boroughs and was pleased when I read the Enfield policy. We were pleased that they (Enfield) did IVF treatment for same sex couples. As a group we were horrified when we looked at the comparison and that some of the boroughs did not offer IUI – we were in agreement that there needs to be equality across the five boroughs and same sex couples should not to be discriminated against. ▪ The boroughs that don't offer more for same sex couples are at risk of having a huge lawsuit if they are not careful in not providing services based on sexual identity which is clear discrimination. ▪ As far as the number of cycles is concerned (IVF 1-3). Not an expert but as long as it is the same across the five boroughs cannot see that it matters – it will matter to people the more chances they have the better but I recognise that funding is an issue in the NHS at the moment and will probably always will be. ▪ Providing information on the policies key variations was beneficial – I and the members that attended the meeting last night felt that variations were unfair.
Forum+ CI LGBT Network interview	1	<p><u>Details</u></p> <ul style="list-style-type: none"> ▪ White Irish female, Christian, lesbian 35-44 <p>Headlines</p>

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| | | <ul style="list-style-type: none"> ▪ From our perspective I think there shouldn't be inconsistency around IUI for female same sex couples – I would like to see it there for all same sex couples across NCL in a single policy. I understand there is cost implications for the CCG which may have an influence and would like to understand that if in the future IUI is not offered across NCL. ▪ When you look at the number of IVF treatments offered across NCL for women under 40. There is again inconsistently across the boroughs (Camden up to 3 and elsewhere you can be down to 1). Without thinking too much of cost implications where it can be merged into one policy you go to the best possible offer for all residents. ▪ VF/ICSI – 3 out of 5 Boroughs provide a service – in a perfect world you would like to see them uplifted for them all. Would like to see the cost implications – I understand the need to balance public money for the public good. ▪ Why did you get a difference in each policy in relation to same sex couples – outside of cost is there a completion with opposite sex couples winning out. This is key – and you may be challenged at a future point. ▪ Would suggest counselling for people who are unsuccessful as I know it has been harrowing experience for some people. Haven't heard much about support offered to people. Especially aftercare with access to counselling. In relation to the LGBT community I am not aware of specific support services but hope that they are offered support the same as opposite sex couples. ▪ Identity Responsive Services is discussed a lot at the moment which could be provided at a future point to LGBT patients using fertility services. This would be down to the individual but other people are more comfortable with using LGBT specific services. Perhaps this should be considered for counselling. A lot of people would be happy with whoever is available as most people should be trained to be inclusive. Some people would prefer to use Identity Responsive Services. ▪ Eligibility criteria needs to be clearly explained at the beginning of the journey. ▪ Would welcome an Equality Impact Assessment before the single policy is approved. ▪ Would also welcome to see the costs of each treatment and outcomes achieved. ▪ Interviewees felt that reasons for language is noble but you need to be accurate. This will help reduce problems with patients/couples etc. |
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BAME Community focus group	12	<p><u>Details</u></p> <ul style="list-style-type: none"> ▪ 9 females from Somali community ▪ 3 females from Sudan community ▪ Run with interpreters in Somali and Arabic languages ▪ Non service users <p><u>Headlines</u></p> <ul style="list-style-type: none"> ▪ The group discussed the policies variation slide and there was group consensus when one participant said <i>“people who want to have children should be given help (same sex couples and heterosexual couples). And the NHS should help as much as they can to get the outcome that is needed”</i>. ▪ There was group consensus when one participant said <i>“People have looked at fertility support privately but is very expensive in England and that is why people go abroad”</i>. Another participant went on to say <i>“I thought you had to go privately and didn’t know NHS could support that”</i>. The group agreed that people from their communities prefer to go to Germany/ Egypt/India as it is a lot cheaper getting fertility support. ▪ There was group consensus as the majority of people (10/12) didn’t know policies/procedures and systems. Would like information in the future to raise awareness of NHS fertility support services which would give people the opportunity to access the service. ▪ Sacdia (interpreter) knew about fertility support and of some people who have got help on the NHS (within NCL and outside of NCL) – and waiting times was people’s biggest concern for the people that received support. ▪ Eligibility Criteria – The group felt that the age criteria should be more flexible as some people may not be well or not the right time to have children when they were young. One participant felt it should be to the age of 50. Weight / BMI was greatly discussed and one participant said <i>“most of us are overweight - people would be happy to lost weight if we were given sufficient time – there needs to more flexibility when judging people on BMI”</i>. The group agreed with the participants comments. ▪ 10 of the twelve participants were not aware of the help that is available on the NHS.
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		<ul style="list-style-type: none"> ▪ One participant said that “Fertility is not always the women’s fault as I know of an occasion when a man was the problem – they both went for tests in the NHS - she couldn’t read or write English – he told her she was the problem – the same went to Germany and she was told she had the problem - she eventually found out it was him -divorced him and has now had a child. Someone read the letter and told her that he had the problem. Why should IVF not be told separately? Men are usually better educated. They were married for 10 years. Someone asked her could they see the letter. Happened a couple of years ago”. ▪ Participant said (group consensus) that “In Islam a man is allowed to marry four wives – you have to get pregnant – women has a lot of pressure to get pregnant. The NHS could do a lot more to help people with emotional support”.
BAME Community focus group (FPR)	3	<p><u>Details</u></p> <ul style="list-style-type: none"> ▪ Members of the public from Barnet and Enfield <p><u>Headlines</u></p> <ul style="list-style-type: none"> ▪ The group asked the CCG ensure it had robust data to inform decision making on fertility moving forward. ▪ The spokesperson confirmed that Human Fertilisation and Embryology Authority (HFEA) are producing a country-wide report, with things such as ethnicity and how it relates to fertility services, included. ▪ Respondent pointed out that she suspects some people don’t know about the treatments available to them and that there is a stigma around fertility within some cultures. Pressure can be put on women but it can be the male partner’s issue, which puts undue pressure on women. ▪ A respondent outlined that the option of 3 cycles would be more useful than one, and wouldn’t necessarily be required for every patient, adding that the option of only one cycle feels like an insult and adds unnecessary pressure to the patient. ▪ The group felt that best practice is what should be adhered to, adding that it is already difficult for people in some communities to discuss fertility treatment, but if they are also in a same sex relationship you are already at an even bigger disadvantage. ▪ The group felt that the NHS assumes that young people are not concerned, but that it is important to included younger people. If you are talking to people about general health, it is important to point out ‘have you considered this for the future’ as by time

		they try to access the services, their lifestyle/health choices may have negatively affected potential successful outcomes.
Briefing for NCL Healthwatches	3	<p><u>Details</u></p> <ul style="list-style-type: none"> Representatives from Enfield, Haringey and Islington Healthwatches attended. Barnet and Camden were invited, but unable to attend. <p><u>Headlines</u></p> <ul style="list-style-type: none"> Group consensus that there would be more service user/resident engagement once the CCG presents a draft single policy for feedback. Group felt from the engagement undertaken that the CCG had been inclusive in their engagement approach with approach local LGBTQ+ groups, ethnic minority groups and people whose Country of origin was the not the UK.
Discussion group with Haringey LGBTQI+ network	13	<p><u>Details</u></p> <ul style="list-style-type: none"> Attendees comprised members of the Haringey LGBTQI+ network <p><u>Headlines</u></p> <ul style="list-style-type: none"> Concerns were expressed in relation to the provision of services for same sex couples across NCL. Can you make it clear that the single policy covers all LGBTQI+ people. You don't mention Trans people for instance. "Trans or non-binary is not mentioned in the policies". This needs to be addressed in the single policy.
NCL CCG Community Member focus group	4	<p><u>Details</u></p> <ul style="list-style-type: none"> Community Members from all boroughs except Islington, who sent apologies. <p><u>Headlines</u></p> <ul style="list-style-type: none"> A respondent feedback that the most interesting bit to me is the cycles for IVF treatment – "I appreciated the access problems for the BAME community. Now is Camden and Islington boroughs that have their services better funded. My experience is that it is much easier to add a cycle to a policy than to take away a cycle". There was group consensus that "at the next stage will we have a paper that says if we go back up to Camden level (IVF) it will cost x amount of £s. If it is not costed at the next stage it would be difficult to take it out to stakeholders. This is required". There was group consensus on "When you are looking at the slides it is easier to look at the IVF cycles which leads people's thinking and questioning. The other

		<p>aspects of the fertility policy – we are thinking of it on a one-axis. Is it more complicated than this – is there more issues that we should be looking at here. Camden doesn't do other things. Could it be laid out better? I don't think the slide is terribly helpful – it makes you make comparison rather than what is best.</p> <ul style="list-style-type: none"> ▪ It would be good moving forward if you knew the outcomes by borough as it would help the decision making – (group agreed that you want cost and the outcome). If spending a lot of money and nothing happens – that is very different (group consensus on using this approach for stage 2 public engagement). ▪ A respondent said that we have to bring policies in line together. A lot of BAME communities haven't considered doing the cycle for IVF – a lot have gone for private treatment. We have to look at BMI – if you are a large person – should they have access to a dietician to help them.
Enfield PPG Forum meeting	8	<p><u>Details</u></p> <ul style="list-style-type: none"> ▪ Representatives from 8 Enfield practices <p><u>Headlines</u></p> <ul style="list-style-type: none"> ▪ About time this was an overall policy and not different in different areas. One experience where the fertility programme had begun here (Enfield), the person had to move to a different part of the country (outside of NCL) where continuing treatment was refused. She had to reapply to start again – by then coming up to 40th birthday and was not allowed to carry on. It would be good for all organisations to have a common policy. Hard work but worth the effort. ▪ Even if no experience of IVF – it is good to add comments to the general principles e.g. good to have standard policy, good to have consistency of access, abbreviations/language confusing, as an Enfield resident I would expect the same access as a Camden resident. The more information that is captured the better the policy will be.
Barnet Adults and Communities Involvement Board	12	<p><u>Details</u></p> <ul style="list-style-type: none"> ▪ Resident representatives from the Barnet Council-led Involvement Board <p><u>Headlines</u></p> <ul style="list-style-type: none"> ▪ The group supported a single policy principle across NCL and agreed to disseminate the online questionnaire and papers for information.
Camden Patient and Public Engagement Group (CPPEG)	12	<p><u>Details</u></p>

		<ul style="list-style-type: none"> ▪ Stakeholder representatives who sit on CPPEG, including Healthwatch, Age UK, Voluntary Action Camden and PPG members <p>Headlines</p> <ul style="list-style-type: none"> ▪ Would like to know more about the eligibility criteria in the different boroughs and how that differs. ▪ Would like to know how resources are allocated, patient experience and outcomes to make more of an informed judgement ▪ A question is about the future – you hear in the media about lowering sperm count amongst men and difficulties with women trying to have babies at an older age. Is this a growing area of concern and is numbers likely to change over time. ▪ Interested in seeing the variation within NCL – are we going to be collecting data from the different GP practices and the different boroughs because I would imagine that different practices/boroughs would perform at different levels on this ▪ I looked at the online questionnaire and it is difficult to fill in if you haven't experienced the services without reading the policies. I don't think the service affects a lot of people although the variation slide deck does help
Barnet Primary Care Engagement Group	9	<p>Details</p> <ul style="list-style-type: none"> ▪ Stakeholder representatives who sit on the group, including CommUNITY Barnet, GP Federation, Inclusion Barnet (Healthwatch) and PPG members <p>Headlines</p> <ul style="list-style-type: none"> ▪ The group supported the aim for a single policy across NCL and agreed to support the dissemination of the survey and public website to its members.
Enfield Voluntary and Community Stakeholder Reference Group	11	<p>Details</p> <ul style="list-style-type: none"> ▪ Stakeholder representatives who sit on the group, including Healthwatch, Age UK, Enfield Racial Equality Council, Enfield Voluntary Action, Enfield Over 50s Forum, PPG Chair, Enfield Women's Centre and Our Voice <p>Headlines</p> <ul style="list-style-type: none"> ▪ Wanted to know whether if CCG is undertaking any work with regards to uptake with regard to ethnic minorities as I know there is certain cultural issues that you should consider ▪ Asked if there is any work in regards to counselling in relation to when people are going to be referred or not referred & in relation to whether they will get treatment.

		<ul style="list-style-type: none"> There are stigmas and pressures that people from certain communities may face and there needs to be issues that you should consider very seriously. In many cases you would have extended families that may be involved and bring pressures onto individuals.
Camden Parents Advisory Board	10	<p>Details</p> <ul style="list-style-type: none"> 10 parents attended the meeting, but did not want their names recorded <p>Headlines</p> <ul style="list-style-type: none"> The review needs to incorporate policies with regards to the BAME community. This should be in the form of a current comparison of BAME recommendations for fertility treatment, uptake and success of treatment. This is a group which medically relies on more support, and is currently not considered, let alone be given the extra support/treatment needed. Any policy should be specifically inclusive of them catering to their specific needs.

Appendix 2: Survey demographic data

In total there were 53 responses to the survey. The highest number of responses were from people living in Camden.

Borough	Number of responses received
Barnet	6
Camden	18
Enfield	4
Haringey	7
Islington	4
Other	13*

*two said they were registered with GPs in one of the boroughs

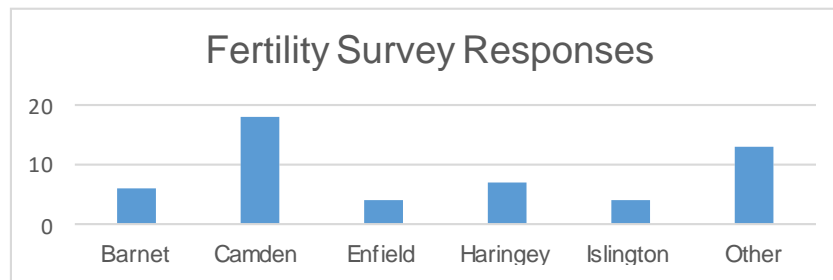


Fig. 2 Number of survey responses received by borough

The majority of responses were from people aged between 35 and 44 year. This group constituted 47% of the responses. 15% of people who responded said they preferred not to divulge their age.

Age	Number of responders
25-34	12
35-44	25
45-54	7
55-64	5
Prefer not to say	3

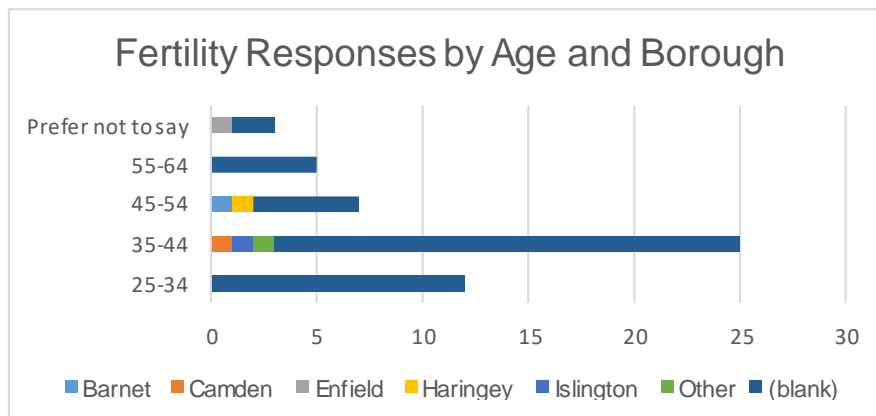


Fig. 3 Survey responses by age and borough

By far the majority of respondents were female, making up 81% of the total. Most of this group were aged 35-44 years. The survey included one female respondent, aged 35-44 years, who

report a different gender identity to that which they were given at birth. Men constituted 15% of the respondents, falling mostly in the over 45 age group.

Gender	Number of responders
Female	42
Male	8
Prefer not to say	2

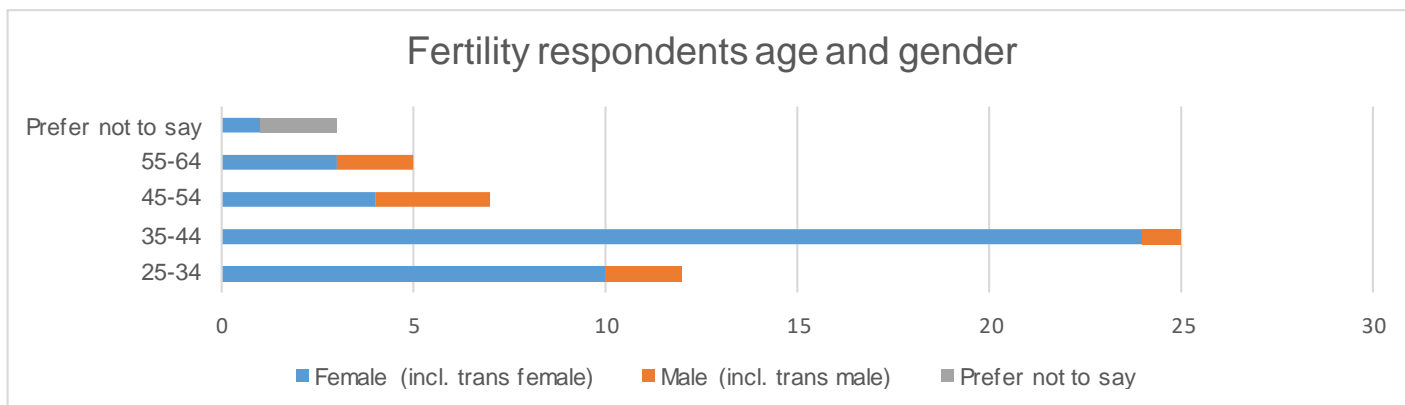


Fig. 4 Survey respondents by age and gender

Gender same as at birth	Number of responders
Yes	47
No	1
Prefer not to say	4

83% of respondents did not declare any disability and 10% of respondents responded that they considered themselves to have a disability. 7% of respondents either did not respond, or preferred not to divulge their disability status

Do you consider yourself to have a disability	Number of responders
Yes	5
No	43
Prefer not to say	4

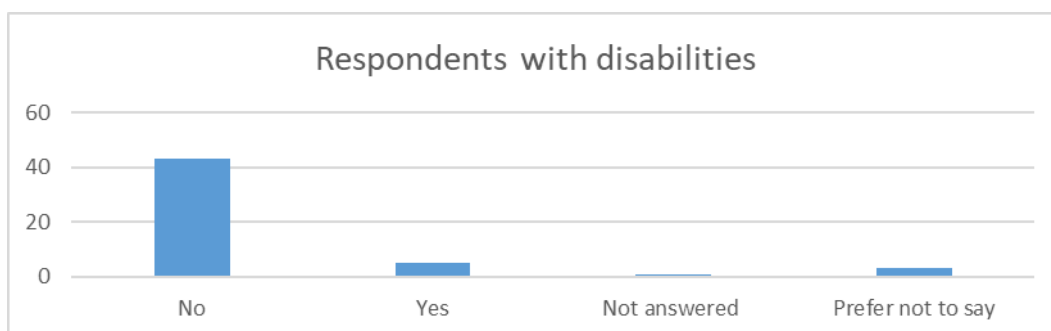


Fig. 5 Respondents with disabilities

65% of respondents were from White backgrounds, of which 35% were females identifying as White British aged between 25-44yrs. 13% of respondents were Asian, approximately 6% were from Black

background and 2% were from mixed background. 14% of respondents either did not answer this question, or preferred not to say.

Ethnic origin	Number of responders
Asian/Asian British: Any other Asian background	1
Asian/Asian British: Indian	5
Asian/Asian British: Pakistani	1
Black or Black British: Black African	3
Mixed – any other mixed background	1
White: Welsh/English/Scottish/Northern Irish/British	23
White Irish	3
White: Any other white background	8
Prefer not to say	7

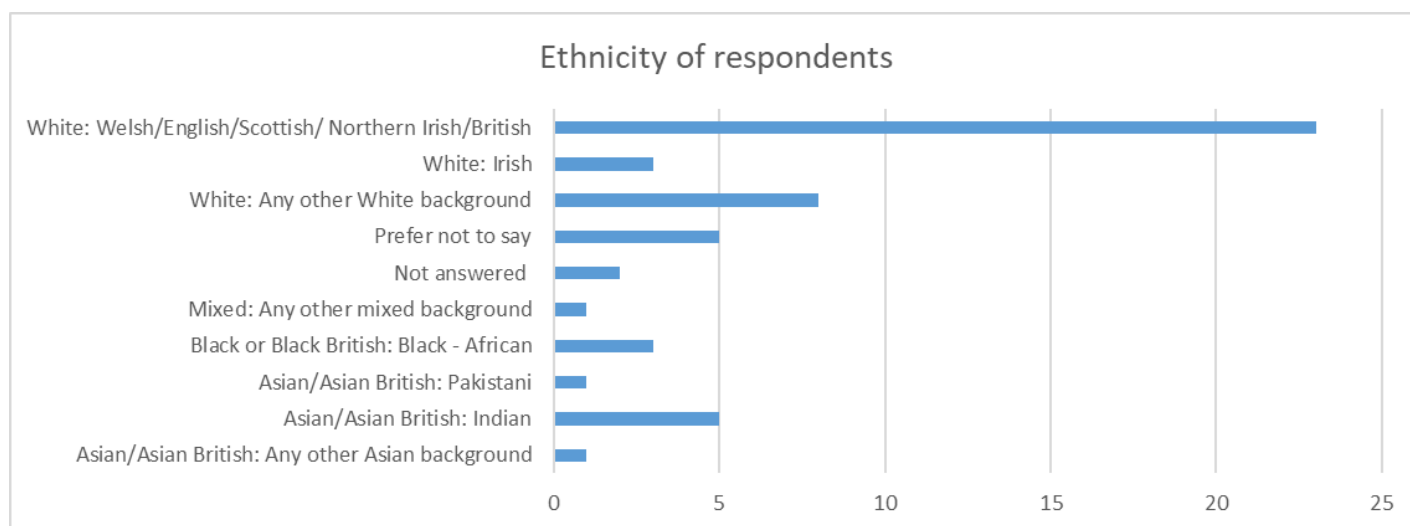


Fig. 6 Ethnicity of survey respondents

33% of respondents said that they had no religion, of which 29% were females aged between 25-44 years. 29% of all respondents gave their religion as Christian, of which 73% were aged 35-44. The next highest stated religions were Jewish and Muslim, both at 8%. 12% of respondents preferred not to give their religion.

Religion	Number of responders
Atheist	3
Christian	15
Hindu	1
Jewish	4
Muslim	4
Sikh	1
No religion	17
Any other religion	1
Prefer not to say	6

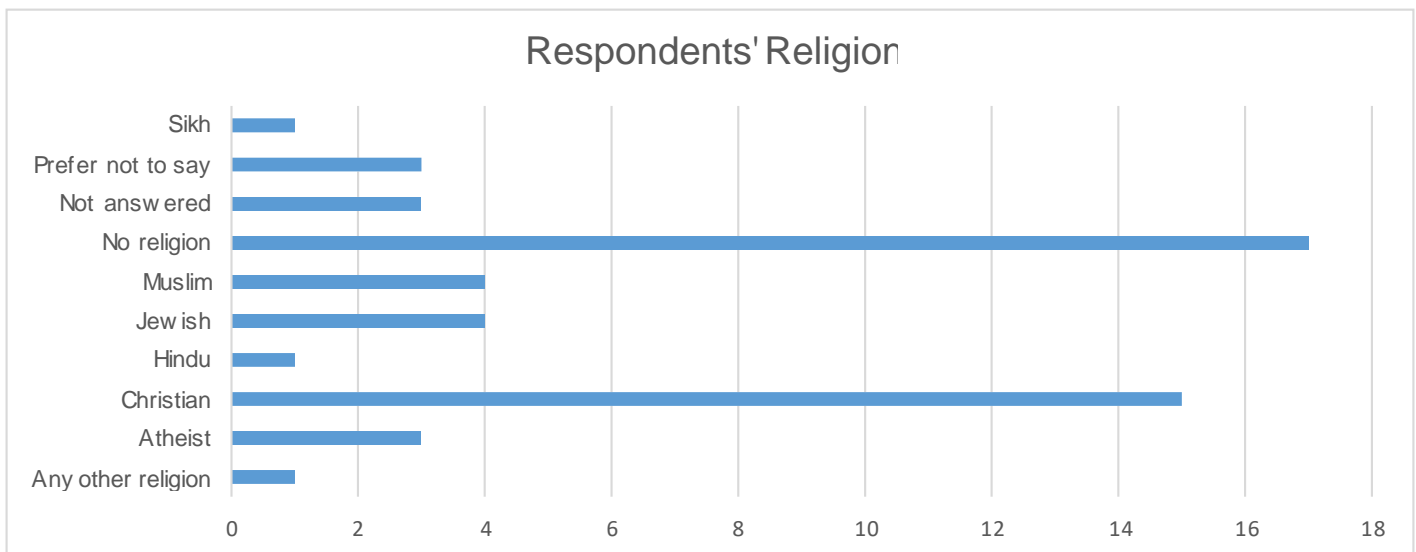


Fig. 7 Survey respondents' religions

85% of respondents to the fertility survey described their sexual orientation as heterosexual, 5% bisexual, 2% lesbian and 8% did not answer or preferred not to say.

Sexual orientation	Number of responders
Bisexual	3
Heterosexual	44
Lesbian	1
Prefer not to say	4

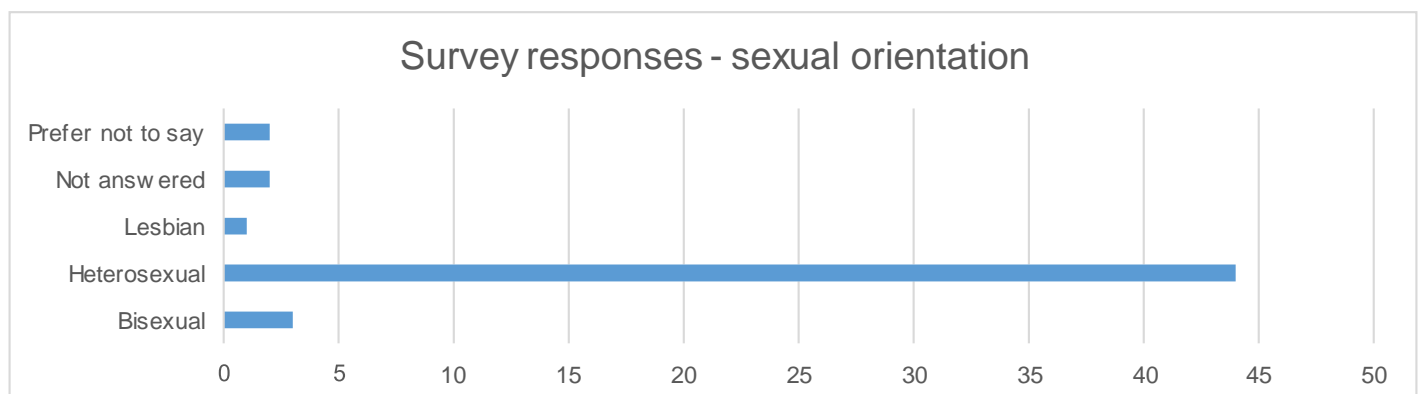


Fig. 8 Survey responses – sexual orientation

45% of all respondents were former service users, of which 20% worked in healthcare. 19% of respondents worked in healthcare, 23% of respondents were from the general public, 1% from the voluntary sector and the remaining 12% preferred not to say.

The above included responses from at least 3 GPs, 2 NHS Staff and 1 from the Fertility Network, whilst the remaining preferred not to divulge further information on their roles and organisation.

Capacity in which answering	Number of responders
Member of the public	12

Current/former patient or service user	19
Current/former patient or service user AND Health or care professional/NHS staff	5
Health or care professional/NHS staff	9
Fertility service provider	1
Voluntary organisation/charity	1
Not answered	5

Responding as the representative of an organisation	Number of responders
GP	3
NHS	2
Voluntary organisation/charity	1
Not answered	46

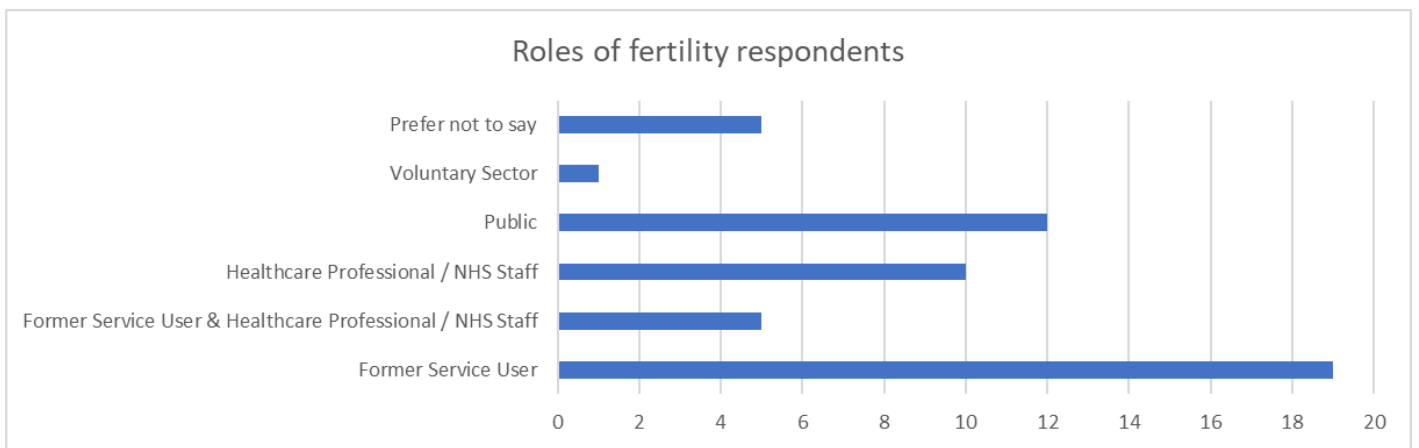


Fig. 9 Roles of those responding to the survey

Appendix 3: Engagement log

Barnet	
Organisation	Response
Community Barnet	Shared the information and Community Barnet disseminated the links and online questionnaire with their networks. Also supported the Review by sharing social media content – members of the Fertility Policies Review team presented the core slide deck at a member meeting.
African Cultural Association	Information shared and CCG team spoke to the association requesting their help in promoting the BAME focus group.
Barnet Multi Faith Forum	Shared the information and the forum disseminated links and online questionnaire with their networks.
Age UK Barnet	Information shared with Age UK Barnet.
Barnet Carers	Information shared with Barnet Carers.
Barnet Parent Carers	Information shared with Barnet Parent Carers .
Inclusion Barnet (Healthwatch)	Information was shared with Healthwatch and they helped promote by sharing with their networks. Also supported the Review by sharing social media content
Chinese Mental Health Association	Information shared with the Chinese Mental Health Association.
Young Barnet Foundation	Information shared with Young Barnet Foundation.
Disability Action Barnet	Information shared with Disability Action Barnet.
Barnet Mencap	Information shared with Barnet Mencap.
Barnet Seniors Association	Information shared with Barnet Seniors Association.
Grahame Park Community Centre	Information shared with Grahame Park Community Centre.
Sangam Centre	Information shared with Sangam Centre.
Barnet Borough Sight Impaired	Information shared with Barnet Borough Sight Impaired.
New Barnet Library	Information shared with New Barnet Library.
Barnet Minds	Information shared with Barnet Minds.

Camden	
Organisation	Response
Voluntary Action Camden	Information shared and VAC disseminated information via their networks. The members and readership of VAC e newsletter represent the key Umbrella VCS orgs in Camden.
Forum+	Information shared and Forum+ disseminated the online questionnaire and public meeting dates with their members.
Somali Cultural Centre	Information shared with the Somali Cultural Centre.
Parents Advisory Board Camden	Information shared and members of the Fertility Policies Review team presented the core slide deck at a member meeting.
Winsvisible (Women with visible and invisible disabilities)	Information shared with Winsvisible.
The Luton Roma Trust (London based)	Information shared with the Luton Roma Trust.
Camden BAME communications working group	Information shared with the Camden BAME communications working group.

Camden Disability Action	Information shared with Camden Disability Action.
West Hampstead Women's Centre	CCG team spoke to the Centre Manager, but they did not feel that it was appropriate to contact members about the review. Explained the purpose of the review but declined to share.
Bengali Workers Association	Information shared with the Bengali Workers Association.
Camden Faith Leaders Forum	Shared the information and the forum disseminated the links and online questionnaire with their networks.
London Irish Centre (London based)	Information shared with the London Irish Centre.
Young Camden Foundation	Information shared with the Young Camden Foundation.
Eastern European Forum (London based)	Information shared with the Eastern European Forum (London based).
Hopscotch Asian Women's Centre	Information shared and the center disseminated the information via their networks.
Visually Impaired Camden	Information shared and they agreed to forward information we provided via the VIC network.
Chinese Community Centre	Information shared with the Chinese Community Centre. A member of the team also spoke to Centre staff about the review.
Home-start Camden & Islington	Information shared with Home-start Camden & Islington.
Camden Patient and Public Engagement Group	Information shared and members of the Fertility Policies Review team presented the core slide deck at a member meeting.
Age UK Camden	Information shared with Age UK Camden..
African Health Forum	Information shared and the Forum disseminated information via their networks.
Special Parents Forum	Information shared, but the topic is a little off core subject. Agreed to share anything that seeks resident engagement.
MIND in Camden	Information shared with Mind in Camden.
Camden Communities Centres Consortium C4	Information shared with C4.
Healthwatch Camden	Information shared and Healthwatch Camden disseminated the links and online questionnaire with their networks. Also supported the Review by sharing social media content
Camden Carers Centre	Information shared and Camden Carers Centre disseminated the links and online questionnaire with their networks. Also supported the Review by sharing social media content
London Gypsy and Travelers	Information shared with London Gypsy and Travelers.

Enfield

Organisation	Response
Enfield Voluntary Action	Information shared and EVA disseminated information via their networks. The members and readership of VAE represent the key Umbrella VCS orgs in Enfield.
Enfield Connections	Information shared with Enfield Connections.
Enfield's Voluntary and Community Stakeholder Reference group	Information shared and member of the CCG team attended the May meeting to present and take questions and comments. The members of this group represent the key umbrella VCS orgs in Enfield and also cover the 9 protected characteristics.
Enfield Disability Action	Information shared with Enfield Disability Action.

Enfield Multi Faith Forum	Information shared with Enfield Multi Faith Forum.
Enfield Women's Centre	Information shared with Enfield Women's Centre.
Healthwatch Enfield	Information shared and Healthwatch Enfield disseminated the links and online questionnaire with their networks. Also supported the Review by sharing social media content.
Enfield LGBT	Information shared and information was disseminated via their networks.
Edmonton Community Partnership	Information shared with Edmonton Community Partnership.

Haringey	
Organisation	Response
Bridge Renewal Trust	Information shared and BRT replied that although they did not have a suitable imminent VCS meeting, they would include our information in their weekly bulletin. CCG team confirmed details of virtual meetings and ways to feed back.
Nafsiyat	Information shared with Nafsiyat.
Healthwatch Haringey	Information shared and Healthwatch Haringey disseminated the links and online questionnaire with their networks. Also supported the Review by sharing social media content.
Haringey Wellbeing Network	Information shared with Haringey Wellbeing Network.
Wise Thoughts (LGBT)	Information shared with Wise Thoughts and a member of the team talked with members of Wise Thoughts about the review.
Latin American Women's Rights Group	Information shared with Latin American Women's Rights Group.
Groundwork London	Information shared with Groundwork London.
Mind in Haringey	Information shared with Mind in Haringey.
Homes for Haringey	Information shared with Homes for Haringey.
Selby Community Centre	Information shared with Selby Community Centre.
Embrace UK	Information shared with Embrace UK.
Turkish Cypriot Women's Group	Information shared with Turkish Cypriot Women's Group.
Carers Forum	Information shared with Carers Forum.

Islington	
Organisation	Response
LBI young people engagement coordinator	Information shared with LBI young people engagement coordinator.
Body & Soul	Information shared and Body & Soul advised that they would confirm details of what had been done to our generic email address.
Islington Multi Faith Forum	Shared the information and the forum disseminated the links and online questionnaire with their networks.
Diverse Health Voices (Healthwatch Islington)	DHV felt that it was too early to engage during the first stage of the Review and that they would be looking to support engagement more during the second stage. HWI did promote this engagement (survey and events) in their newsletter and through Twitter. Although we've not submitted a response at this stage we'll make some time to do so in phase 2.
The Parent House	Information shared with the Parent House.

Manor Gardens and Bright Start	Director advised that they had not been able to promote the Review, but that they would distribute the online questionnaire to their members, which are primarily hard-to-reach minority groups
Voluntary Action Islington	Information shared and VAI disseminated information via their networks. The members and readership of VAI represent the key Umbrella VCS groups in Islington.
Stonewall	Information shared with Stonewall.
Opening Doors London	Information shared with Opening Doors London.

Patient special interest groups	
Organisation	Response
Fertility Network UK	One of the CCG's Community Members is a staff member of FNUK. NCL CCG and FNUK collaborated to run a focus group during the engagement window.
British Pregnancy Advisory Service	Information on the Review was shared, but no response received from BPAS.
Chana	Information shared and Chana acknowledged the pause due to COVID-19 operational pressures. Further information was shared once all elements recommenced, but no response was received.
IVF Babble	Information shared and CCG team spoke to IVF Babble. They prepared material and shared as a news item on their website . They also asked that we keep them informed as to updates on the Review.
Endometriosis UK	Information shared with Endometriosis UK.
Association of Reproductive Specialists and Clinical Scientists	Information shared with Association of Reproductive Specialists and Clinical Scientists.
The LGBT Mummies Tribe	Information shared and The LGBT Mummies Tribe offered to share across their social media channels and support groups. Our CRO and Programme Director recorded an Instagram live session with the co-founder, which was shared on their Instagram page (resulting in more than 350 views) and also uploaded to our YouTube channel. The link was shared via the CCG's social media platforms.
SING – Senior Infertility Nurses Group	SING responded to our initial information sent and offered to share with their nurses.
British Fertility Society	BFS responded to our initial information sharing and asked what input we would like. We requested a meeting to discuss how we could collaborate to engage with the public, but received no response.
Donor Conception Network	Information on the Review was shared, but no response received from BPAS
Stonewall	Information shared with Stonewall.
Fertility Road	Information shared with Fertility Road.
Verity PCOS	Information shared with Verity PCOS.
Peanut	Information shared with Peanut.
RCOG Women Voices Involvement Panel	Information shared with RCOG Women Voices Involvement Panel.
Daisy Network	Responded to our initial information sent, advising that it had been shared with their team, who would be in touch if they could assist.
British Infertility Counselling	Information shared with British Infertility Counselling.

Appendix 4: Written responses received from survey responses

3 cycles of IVF

- *“NICE recommends 3 full cycles and the provision of only 1 creates a real inequality in term of access to care for infertility”*
- *“The difference between one and three cycles in adjacent boroughs can make all the difference.”*
- *“A minimum of 3 cycles is just, reasonable and provides couples with a reasonable chance of conception and is line with current evidence.”*
- *“It is vital that the NICE guidance on what constitutes a “full” cycle is followed.”*
- *“1 cycle does not provide a fair chance to those who need it”*
- *“The number of cycles is clear that a minimum of 3 should be offered”*
- *“When you use the NICE definition of a full cycle, the numbers of patients eligible will fall after each embryo transfer. Offering a second and third full cycle becomes less expensive as there are fewer patients, but gives a good chance of pregnancy.”*

Psychological support

- *“...suffer very difficult mental health consequences as a result of their ongoing infertility.”*
- *“My mental health suffered greatly and I went to my GP to try and get answers,”*
- *“Firstly you need to consider how fragile people are when they aren’t able to do what we perceive to be our reason to exist. We are not a number. We are people and we are scared. When we ask for help to have a baby we are already a little bit broken but we are also very brave and very determined and many of us already know in our hearts that asking for help is the start of a very lonely and painful journey that may never give us the baby we crave.”*
- *“Please consider including a provision about counselling. The Guys hospital counselling I had, in particular, was so valuable to me. I think this service is crucial alongside the rollercoaster of treatment.”*
- *“This is a chronic medical condition that affects patients who may never have stepped foot into a hospital. They are scared, distressed and desperate.... The policy should include comprehensive health screening, psychological support...”*
- *“This has an effect on their mental health, domestic violence, cost to the NHS due to ill health.”*
- *“My AMH was 1.2, which was considered too low. It broke my heart as you can imagine, and my mental health suffered dreadfully.”*
- *“the thought that I am getting old and could approach the forties without giving closure to this process is quite daunting.”*

- *"I think any money 'saved' by not offering treatment according to the NICE guidelines is lost further down the line in mental health services anyway."*
- *"This does inadvertently put a lot of pressure on as a patient knowing you only have one shot at this before having to consider finances. This is not an elective procedure, the physical and emotional turmoil of fertility treatment is not something anyone would choose to have to go through, yet the hoops we have to jump through are really not aligned with what the NHS stands for."*
- *"We would like to see the devastating emotional impact of fertility problems taken into account, and infertility recognised as a disease as classified by the WHO."*

Holistic Assessment & Treatment

- *"2nd Opinionmy thyroid was within NHS acceptable guidelines however was too low to conceive"*
- *"The process is not clear and the bouncing between gynaecology, urology, andrology, fertility and general practice causes significant stress, confusion and a feeling of helplessness for patients."*
- *"issues such as male factor infertility could actually be due to other medical problems that need treatment such as diabetes or other endocrinopathies."*
- *"Referral to right agencies i.e. dietician,"*
- *"As a single woman with PCOS I was told by an Islington NHS doctor aged 21 that I would have problems conceiving, yet no further investigation or support was offered."*
- *"We were referred for tests which identified my husband is infertile due to cancer treatment as a child. ...Following this we had established a treatment plan with our specialist and were due to start IUI the following month using a donor. It was at this point the consultant rechecked the Camden policy and identified that we were now ineligible due to the need to use a donor (despite all the donor related costs covered by ourselves). In our situation, we have no other option than to use a donor due to a medical reason."*
- *"Think more needs to be done to explore male infertility and emphasis a little more on their health and contribution. Could learn a lot from Prof Lewis on this."*
- *"Subfertility could herald conditions such as diabetes and in fact fertility could be seen as a screening method for other conditions, both male and female related. The range of treatments should be clearly evidenced based, and if there is no evidence, should involve experts panels and lay people from a range of specialties including psychology and urology."*

Pathway review

- *"An AMH blood test very early on could have prevented months of Clomid and heartache."*
- *"After over a year of trying to conceive, I went to my GP who did blood tests and referred to fertility services. There I was sent for a Fallopian tube scan which was inconclusive and not repeated. I was then put on 6 months of Clomid. At no point did I receive a scan of my eggs or have an AMH blood test. I was seen by a range of gynaecologist s and never actual fertility specialists. After Clomid I was referred for IVF which took some time, once that was approved I*

then waited for an IVF appointment. Finally 1yr-18months later I had an appointment at guys. There I had a scan that revealed I only have one egg and an AMH blood test confirms this. This is beneath the NHS threshold for IVF. I was devastated.”

- *“GP’s follows set pattern where all blood tests and Fallopian tube scans are ordered immediately. A scan of the cervix and egg reserves and an AMH blood test should all be undertaken. From there IVF referrals for those with a narrow window should be immediate, those with a higher egg reserve but unexplained infertility should do a maximum of three months on Clomid (but not six).*
- *In tandem someone should be looking at secondary issues like thyroid or diabetes etc. which can impact.”*
- *“...increase accessibility of the consultants”*
- *“What never made sense to me was using the fertility services and never seeing a specialist. Yes they were Gynaecologists but they weren’t fertility experts. Whilst I appreciate that seeing the head of early pregnancy is good, seeing someone who deals with fertility day in day out is better.”*
- *“confusing pathway, lack of direct ref form Gynae specialist to the fertility clinic-why does it need to go via GP?”*
- *“...the main treatment barriers were the lack of join up between investigative procedures to determine infertility and subsequent treatment. There was duplication of tests which meant additional time off work”*
- *“...this is proof that it's not about quantity of eggs, but quality of eggs. Our Dr was very clear she had no issues with us getting pregnant because we were young, but unfortunately the system did not seem to consider rare cases like mine, and because of this I feel that we were unjustly denied IVF Funding. I would like to ask the CCG when considering these policies to take in to consideration woman who have premature ovarian failure, and to look at stats for young woman”*

Time

- *“The one thing that none of us has when trying for a baby is time. So much time was wasted and never properly managed.”*
- *“Stop wasting time....we simply don’t have it!”*
- *“I saw my GP in a November about my difficulty conceiving (and following a miscarriage) to be referred for treatment. It was the following MAY that I had my first appointment at Guy’s hospital and ultimately heard the traumatic news that my AMH and chances were extremely low. In that wasted 7 months waiting for my appointment I had a birthday which meant that I only had one cycle offered.”*

Donor Eggs / Donor Sperm / IUI

- *“I think donor assisted routes should be factored into the standardised policy.”*
- *“3 cycles of IUI which has very low success rate”*

- *“Donor eggs should be included.”*
- *“6 cycles of IUI can cost up to £30,000 in a clinical setting. NICE does not stipulate insemination must happen in a clinical setting”*

Frozen Embryo Transfer (FET)

- *“The policy should include comprehensive health screening, psychological support, a substantial, evidence based funding package with a minimum of at least 3 cycles of IVF with FET.”*
- *“the main issue is standardising number of transfers offered in order to optimise chances of success.”*
- *“A full cycle is not one fresh and one frozen transfer, but rather a fresh transfer and then the transfer of remaining frozen embryos. It is unethical to offer NHS-funded treatment to create an embryo and then to say this embryo can only be stored and transferred if a patient has the funds to pay for this privately.”*

Advice & Information

- *“I was never made aware of egg donation provision (something we ultimately needed) until after 3 cycles of IVF mostly self-funded.”*
- *“Clarity in the provisions is key. Infertility causes a huge amount of grief and fear. This is exacerbated by a fog of differing information.”*
- *“Guys hospital and Lister hospital (who we subsequently moved to for donor assisted treatment via Spain) had donor egg information but it came later after IVF attempts with own eggs.”*
- *“A leaflet summarising the fertility pathway within NCL would be helpful to give to patients at the time of referral by their GP.”*

GP / Nurse Education

- *“The clinical specialist nurses do not know much and are poor communicators. The wrong prescriptions have been issued.”*
- *“Improve the training of clinical nurse specialists”*
- *“Retrain GP’s.”*

COVID-19

- *“The delays, somewhat expected due to COVID, are unacceptable however.”*

Eligibility Criteria - Feedback

BMI Criteria

- *“I think there should be some flexibility for BMI in older women if the patients for example has regular cycle and does not need to lose weight to improve PCO. I have seen the BMI criteria effectively exclude a number of patients who are simply not able to lose the weight required in the time needed to qualify under the age criteria.”*

Age Criteria

- *“I think women between 40 to 45 should be given the same number of cycles as younger women, reflecting the age ranges that many women are now in a position to start a family with the north London demographic.”*

Ethnicity Criteria

- *“I feel like the fertility treatment is given only to some people and others refused, I have seen a doctor about it several times and no help or hope is given was referred to a specialist several times but I get no help thus to my understanding it was not given to a person of colour, I once had a doctor say that your people have lots of children and I said to her that not me, I have none.”*
- *“I’m concerned about the BMI criteria as this has been shown not to be a good indicator of health particularly for women of colour.”*
- *“The support for the ethnic community on BMI requirement can be reviewed. As a fertility nurse and an African. I’ve seen a few patients not even been processed or supported with high BMI.”*

Second Child Criteria

- *“If one partner has a child but the other does not, this should not rule out a couple for fertility treatment on the NHS”*
- *“It is completely unfair to deem people ineligible because of a previous child. If someone got cancer for a second time they wouldn’t be ineligible for treatment simply because they’d already had it once.”*

Smoking Criteria

- *“The eligibility in part are fair with respect to age, BMI and Smoking as these latter 2 are modifiable.”*

Single Person Criteria

- *“I think you should support single women to have fertility treatment incl IUI”*

LGBTQ+ Criteria

- *“Same sex couples should be included where the issue is one of fertility.”*
- *“It saddens me that I could have walked into my GP with our sperm donor – my wife’s cousin – shown no evidence of subfertility but to say we’d been trying for a year, and we would have been granted immediate investigations and IVF treatment if required. That the same support is not afforded to my wife and I and we effectively have to pay to access NHS services. As far as we are concerned, this policy stance amounts to unlawful direct discrimination under the Equality Act 2010 on the grounds of our sexuality.”*
- *“It should cover all donor treatment for heterosexual couples, same sex couples and single parents. The current policy says that it is non-discriminatory. However, by excluding these groups from coverage, it is discriminatory.”*

Funding – Feedback

No Fertility treatment funded by NHS

- *“...consider whether it is money well spent, once a person’s ability or not to reproduce has been established. We can scarcely afford to treat the people we do have.”*

- *"I question the ethos of offering any fertility treatment at all when there are such limited resources available for health care in general, and when there are >2000 children languishing in the looked after system, waiting for permanent families."*

NHS/ Private

- *"I also think this should be allowed if someone has previously attempted IVF privately before On the NHS."*
- *"Patients are so distressed by infertility that they will re-mortgage houses, buy drugs online (there is an online market for Clomid) and simply do anything to have the chance to conceive. The patient population are vulnerable, desperate and without comprehensive fertility funding liable to and vulnerable from dangerous, non-evidence based and potentially fraudulent practices."*

Means Testing

- *"It should be provided free of charge or people who are trying to have a baby and cannot afford the IVF treatments privately"*
- *"I think access should be based on your personal circumstances."*

Equality of offer across NCL

- *"A change in policy to the lowest number of cycles would be devastating."*
- *"To use the current jargon, I am more interested in levelling up than down."*
- *"I cannot understand the rationale behind the postcode lottery when it comes to accessing fertility treatments."*

Policy

- *"There is no service at all at the weekends- a fertility service must run every day for optimal treatment success."*
- *"I think that the CCG should publicise this consultation further, hold open town halls and be responsive to what local people say."*