





**Report on Mid and South Essex Integrated Care Board (ICB) public consultation**

**Service harmonisation: Bringing equity to services across mid and south Essex**

**31 October – 19 December 2022**

A report by Stand

for Mid and South Essex ICB

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# Executive summary

## Introduction

Mid and South Essex Integrated Care Board want to change the policies for six services that are currently only funded by the NHS in this area under certain circumstances, so that there is one single policy for all the services.

These services are:

* Weight loss surgery (bariatric surgery)
* Correction for uneven breasts (breast asymmetry)
* Breast reduction
* Female sterilisation
* Vasectomy (male sterilisation)
* Special fertility services including: Intra-uterine insemination (IUI); In vitro fertilisation (IVF), with or without intra-cytoplasmic sperm injection (ICSI): Sperm and egg donation (sperm and oocyte donation)

The ICB ran a public consultation about this from 31 October to 19 December 2022. This report analyses the responses from the public consultation.

The public consultation included a survey and a number of engagement events and focus groups. It was publicised widely among stakeholders, websites, in the media and on social media.

The ICB assessed potential health inequalities for different groups within society and approached those likely to be impacted. The consultation document (Appendix 1) and survey (Appendix 2) were available on request in other languages and an easy read version of the document (Appendix 3) was developed.

## Summary of feedback

A total of 210 people responded to the online survey, with one additional paper response being received once the consultation had closed. As the analysis of the online survey had already been completed when this was received, the views of this individual were considered separately.

The people who responded to the online survey were mainly people who:

* are currently affected by this policy as a patient or service user (33%);
* have a close relationship with someone who is affected by this policy or has been affected in the past (18%);
* feel they might be affected in the future (25%); and
* 15% have a professional interest in this policy.

Survey respondents were given the option to select the clinical service areas that they wished to provide their views for or comment on the proposed policy update generally.

Twenty people participated in public events or focus groups. One person in a focus group shared with own views and the views of other people from their organisation.

Most online survey respondents supported the proposed policy updates. The highest levels of support were for special fertility services (78%), bariatric surgery (74%) and vasectomy (72%). For the other clinical service areas – breast asymmetry, breast reduction and female sterilisation - approximately two thirds expressed support for the changes.

Objections to the proposed policy updates were raised by some respondents, including the feeling that further consideration is needed before making the updates, and around the proposed threshold criteria for the services, in particular with regards to special fertility services.

Participants in the focus groups and public events were generally supportive of the changes. That support was tempered with several queries and points for further consideration that were raised about the policy update in general, as well as specifically for the different clinical services.

***Online survey findings***

|  |  |  |
| --- | --- | --- |
| **Service** | **No. of respondents who completed the survey section**  | **Percentage support for policy update\***  |
| Bariatric surgery | 49 | 74% |
| Breast asymmetry | 30 | 67% |
| Breast reduction | 42 | 69% |
| Female sterilisation | 32 | 63% |
| Vasectomy | 32 | 72% |
| Special fertility services | 154 | 78% |
| Proposed policy update (general)  | 12 | 50%  |

*\*Proportion of respondents who strongly support or support the proposed policy update.*

Overall, it was felt that the policy changes would enable equitable access for all residents in Mid and South Essex and remove the ‘postcode lottery’ that currently exists. Further, for some clinical areas i.e., bariatric surgery, breast asymmetry, breast reduction, it was thought that the changes would result in improved quality of life for patients, whilst reducing associated costs for the NHS.

Additional specific benefits were identified through improved access to the other clinical service areas such as vasectomy – allowing men to take greater responsibility of their reproductive choices, female sterilisation – giving women the right to choose this as a form of contraception, and special fertility services – giving childless couples the opportunity to have children.

For those that oppose the updates or feel that further consideration is needed, this mostly related to the proposed threshold criteria for the services – for example, it being too high, concerns around the use and accuracy of BMI as an indicator, and potential discrimination of patients dependent on their age or BMI.

The greatest challenge was made with regards to special fertility services where it was felt that there is opportunity for the threshold criteria to be more inclusive and provide more equitable access for same sex couples, single parents, blended families, and those who have in the past accessed treatment privately. It was thought that the proposed policy update as it stands would result in potential areas of inequalities and discrimination which need to be considered to help avoid further implications, including legal challenge.

It must be noted that there was a small cohort of survey respondents who felt strongly that these clinical services should not be funded by the NHS; it was thought that the money should be better spent on improving basic and/or essential services such as improving access to primary care and cancer services.

When reviewing these clinical services, it was felt important that consideration of the financial implications is made to ensure best use of resources as well as the impact that these changes will have on patients’ mental and physical health, as well as that of their partners and families. Additionally, it was felt important to consider patients’ input, choice, and communication, as well as the time it will take to implement these changes.

## Health Overview and Scrutiny

The ICB presented information about the public consultation to three health scrutiny committees, Essex, Thurrock and Southend. Essex committee noted the report and asked for a further update in February. Thurrock and Southend committees noted the information and asked for an analysis of the consultation at future meetings.

## Miscellaneous responses

In addition to the survey responses 27 emails were received about the consultation. Most were about practical details. One asked whether discussions had been held with the other ICSs in Essex and one expressed a lack of confidence in the consultation process. Replies were sent to all the emails.

## Next steps

The report will be presented to the ICB decision making board on 9 February 2023 in order to make a final decision about the future policies.

# Introduction

## Context

Mid and South Essex Integrated Care Board (the ICB) was formed on 01 July 2022. It is responsible for planning, organising, and buying NHS funded healthcare for the 1.2 million people living across mid and south Essex.

The ICB wants to change the policies for six clinical services that are currently only funded by the NHS in this area under certain circumstances.

These services are:

* Weight loss surgery (bariatric surgery)
* Correction for uneven breasts (breast asymmetry)
* Breast reduction
* Female sterilisation
* Vasectomy (male sterilisation)
* Special fertility services including: Intra-uterine insemination (IUI); In vitro fertilisation (IVF), with or without intra-cytoplasmic sperm injection (ICSI): Sperm and egg donation (sperm and oocyte donation)

At the moment the policies for these six services differ depending on where people live. For example, people living in the commissioning areas of Basildon, Brentwood and Mid Essex can’t access IVF services on the NHS, when people living in other areas of mid and south Essex can. The ICB wants to change these policies, so everyone living in mid and south Essex has the same opportunities.

The ICB therefore ran a public consultation from 31 October to 19 December 2022 setting out their proposals to help bring the old policies into a new single policy for each of the six service areas, in order to understand the views of patients, the public, staff and stakeholders.

This report analyses the responses from the public consultation.

This report was prepared by Stand, an independent expert community of engagement practitioners with a long history of informing policy, strategy, service design and transformational change programmes.

Together Stand’s experienced specialist team holds a range of relevant professional accreditations.

# Methodology

## Engagement activity

The consultation included the following activity

* A survey to gather feedback from the public, those who have and who may use the services
* Engagement events, in person and online
* Focus groups
* Briefing key stakeholders, including Health Overview and Scrutiny Committees

### Survey

The survey was available online and in printed format. Printed surveys (Appendix 2) along with the consultation document (Appendix 1) were distributed to all libraries in mid and south Essex and were available on request from the ICB. An easy read version of the consultation document was also available (Appendix 3).

### Engagement events

Five public engagement events were arranged in geographic locations across mid and south Essex. Four were held in person and one was held online via Zoom, as follows:

|  |  |  |
| --- | --- | --- |
| **Date** | **Place** | **Attendance** |
| 9 November 2022 | Greys | 0 attendees |
| 10 November 2022 | Witham | 1 attendee |
| 22 November 2022  | Basildon | 1 attendee |
| 24 November 2022 | Southend  | 0 attendees |
| 30 November 2022 | Online | 5 attendees |

### Focus groups

Focus groups were held as follows:

|  |  |  |
| --- | --- | --- |
| **Date** | **Group** | **Attendance** |
| 15 December | LGBT Mummies | 1 |
| 21 November 2022  | Microsoft Teams conversation  | 1 |
| 22 November | Online Men’s Focus Group (including reps from Blind Veterans, Agewell, Community 360, Gambling Education Network)  | 10 |
| 15 December | Bariatric focus group | 1 |

## Data protection

All those who participated were informed of the ICB’s and Stand’s data protection policies. Participants’ data has only been used for the engagement activity and held in line with the latest data protection regulations. Every effort has been taken to ensure that these individuals cannot be identified.

## Delivery team

The engagement activity was delivered by the ICB’s communications and engagement team, supported by Stand (see above).

## Equalities and health inequalities

The ICB assessed potential health inequalities for different groups within society and approached those likely to be impacted, who included the LGBT community, Travellers, people with mental health conditions, people with learning disabilities and people from deprived communities. They also made sure that groups representing all the nine protected characteristics received information including the link to the online survey and information about how to access printed copies of the survey and consultation document to take part in the consultation.

The consultation document (Appendix 1) and survey (Appendix 2) were available on request in other languages and an easy read version of the document (Appendix 3) was developed.

Among the wide range of people contacted with information about the consultation were:

* Eight organisations working with Travellers
* LGBTQI + groups.
* Thirty four mental health groups
* Eighty organisations who work with people with learning disabilities. The easy read version of the consultation document was made widely available and approaches were made to run focus groups for this cohort
* Sex workers
* People from minority ethnic groups.
* Faith groups
* Twenty two organisations working with homeless people

The feedback indicated that sometimes people were not willing to talk in groups about the services in the public consultation and were much happier talking on a one-to-one basis because of the nature of the services being offered or because of cultural preferences. Where focus groups could be organised the reports from them have been analysed.

With regard to deprivation, the monitoring data captures the household incomes of people who responded to the questionnaire and shows that 24% had just enough money for basic necessities and little else and 5% don’t have enough money for basic necessities and sometimes or often run out of money. This illustrates that people from a wide range of socio-economic groups completed the survey.

## Publicity and promotion

Information about the public consultation was sent to 37 media outlets. It was also promoted on social media and through communication by email. More than 5,500 people have signed up with the ICB for general news and updates and approximately 800 people have signed up to receive the engagement newsletter, and they were all targeted with information about the public consultation.

The organisations who received information included those listed above in the equalities section, together with public sector partners and neighbours in the NHS and local authorities and 368 mid and south Essex patient and public representatives.

The consultation received widespread coverage in local newspapers, particularly the Basildon Echo and Essex Chronicle, and was picked up by organisations with a special interest, such as Bourn Hall Fertility UK, who promoted it on their Instagram feed.

Information about the consultation together with links to the consultation document and survey was available on the [ICB’s website](https://www.midandsouthessex.ics.nhs.uk/get-involved/consultations/service-harmonisation/), generating 1,096 page views of which 915 were unique. The average time spent on the page was two minutes 11 seconds.

The ICB’s Instagram account put out films to encourage people to take part as the consultation progressed.

There were 58 social media posts with a total of 160 clicks. The reach was 7,200, and with 13,000 impressions. There was a good engagement rate of 2.40%.

## Next steps

The report will be presented to the ICB decision making board on 9 February 2023 in order to make a final decision about the future policies.

This will support their ambition to end the variation that has existed up to now in accessing these services for those who would clinically benefit in mid and south Essex.

# Analysis

## Analysis of survey responses

### Respondent profile

A total of 210 people responded to the online survey, with one additional paper response being received once the consultation had closed, which brought the total sample size to 211.

As the analysis of the responses to the online survey had already been completed prior to the paper response being received, the response from this individual is presented separately (See Section [Additional paper response received](#_Additional_paper_response)). The following therefore presents the findings of the online survey only.

Slightly higher proportions were from Basildon Borough Council (23%), Chelmsford City Council (16%), Southend-on-Sea City Council (14%) and Braintree District Council (12%).

Other areas (5%) included Babergh, Colchester, Epping, Tendring, South Cambs, Uttersford and Cambridge.

Q Please tell us which council area you live in? (N=210)

|  |  |  |
| --- | --- | --- |
| **Area** | **No.**  | **%** |
| Basildon Borough Council | 48 | 23% |
| Chelmsford City Council | 33 | 16% |
| Southend-on-Sea City Council | 30 | 14% |
| Braintree District Council | 25 | 12% |
| Brentwood Borough Council | 19 | 9% |
| Thurrock Council | 14 | 7% |
| Castle Point Borough Council | 13 | 6% |
| Maldon District Council | 11 | 5% |
| Other | 10 | 5% |
| Rochford District Council | 7 | 3% |

A third of respondents (33%) are currently affected by this policy as a patient / service user, whilst 18% have a close relationship with someone who is affected by this policy or has been affected in the past and a quarter (25%) feel they might be affected by this policy in the future.

Furthermore, 15% have a professional interest in this policy, whilst 18% are not affected by this policy in any way.

The majority of those who selected other (7%) indicated that they have been affected by this policy in the past.

Q. Which of the following statements apply to you? (N=210)\*

|  |  |  |
| --- | --- | --- |
| **Response** | **No.**  | **%**  |
| I am currently affected by this policy - patient or service user | 70 | 33% |
| I might be affected by this policy in the future | 52 | 25% |
| I have a close relationship with someone who is affected or has been affected by this policy in the past e.g., carer | 37 | 18% |
| I am not affected by this policy in any way | 38 | 18% |
| I have a professional interest in this policy - staff / clinician | 31 | 15% |
| Other  | 14 | 7% |

*\*Due to the multiple response nature of this question, percentages do not add up to 100%.*

A summary of the demographic profile of the online survey respondents is provided here:

* The highest proportions were aged 25 to 34 years (30%) and 35 to 44 years (26%) (see Figure below).
* 14% were currently pregnant or had been in the last year.
* 82% were White – English, Welsh, Scottish, Northern Irish, or British, with much smaller proportions White Irish (1%), Asian or British Asian – Indian (1%), Black, Black British Caribbean or African – Caribbean (1%) or other (2%) (10% preferred not to say).
* The majority were heterosexual or straight (83%) with much smaller proportions’ bisexual (4%) or gay / lesbian (1%) (12% preferred not to say).
* The majority (87%) stated that their gender identity matches their gender assigned at birth, whilst 1% said it didn’t and 12% preferred not to say.
* 79% identify as a woman (including a trans woman), whilst 10% identify as a man (including a trans man) (11% preferred not to say).
* 90% stated their first language was English, whilst 10% preferred not to say.
* 25% stated having a physical or mental health condition(s) or illness(es) which has lasted or is expected to last 12 months or more. Two thirds of these (68%) indicated that this reduces their ability to carry out day-to-day activities to some extent.
* In terms of their current financial situation:
	+ 46% have more than enough money for basic necessities, and a little spare that they can save / spend on extras or leisure.
	+ 24% have just enough money for basic necessities and little else.
	+ 6% have more than enough money for basic necessities, and a lot spare that they can save / spend on extras or leisure.
	+ 5% don’t have enough money for basic necessities and sometimes or often run out of money.
	+ 19% preferred not to respond to this question.

*Figure 1 Age profile of online survey respondents (N=210)*

The full demographic breakdown of survey respondents, which includes the additional paper response received, is available in [Section 4.3](#_heading=h.2lwamvv). Due to this addition, there is slight variation in the percentages to those presented above.

### Clinical service - bariatric surgery

This section of the survey was completed by 49 individuals. Overall, there was strong support for the proposed policy update with regards to bariatric surgery with 33% strongly supporting and 41% supporting this. In contrast, 16% oppose the changes to some extent. This included individuals from:

* Chelmsford City Council (N=2; 6%\*)
* Thurrock Council (N=2; 14%\*)
* Brentwood Borough Council (N=1; 5%\*)
* Basildon Borough Council (N=1; 2%\*)
* Braintree District Council (N=1; 4%\*)
* Southend-on-Sea City Council (N=1; 3%\*)

*\*Percentages shown as a proportion of respondents from this area.*

Q. To what extent do you support or oppose the proposed policy update? (N=49)

|  |  |  |
| --- | --- | --- |
| **Support or oppose** | **No.**  | **%**  |
| Strongly support  | 16 | 33% |
| Support  | 20 | 41% |
| Neither support/oppose  | 5 | 10% |
| Oppose  | 3 | 6% |
| Strongly oppose  | 5 | 10% |

*Figure 2 To what extent do you support or oppose the proposed policy update? (N=49)*

In terms of support for the proposed policy update, there was agreement that access to this treatment should be fair and available for all. Furthermore, it was thought that providing access will result in improvements to the quality of life of patients as well as being cost-effective for the NHS, reducing longer-term medical costs.

“Important to have unified policy and bariatric surgery is becoming more commonly recommended”

“Can save costs for diabetes - also help improve individuals lives for health and mental health”

Respondents also expressed their support for the threshold criteria in terms of patients needing to demonstrate their own effort to reduce their weight and/or show commitment to long-term follow up.

“Needs to be available to all areas to support weight loss but important it’s not rushed into, and other options tried first as not an easy option. Fully agree there needs to be long-term follow up and support”

For those that opposed the update or felt that further thought was needed, comment was made about the need to consider the counselling / support that must be provided both pre- and post-operatively to help patients address the root causes of their problem, as well as educate them around dietary needs and body image.

“Psychological support for this issue is one of the most important aspects that need to be looked at”

Comment was additionally made about the threshold criteria in terms of it being ‘too high’ with ‘too many obstacles for patients to overcome’, this included the use and accuracy of BMI as an indicator, as well as a feeling that NHS funding should not be used in this way.

“The use of BMI is a very crude and generally ineffective means of determining need - an athlete (especially those who undertake weight training) will almost certainly achieve a high BMI but have very little actual fat. Fat density and distribution scans would be far more effective.”

“It depends on there being sufficient funding in the system without affecting provision for major life-threatening conditions such as cancer, heart problems etc”

Q Please explain your response (N=45)\*

|  |  |  |
| --- | --- | --- |
| **Support / positive comments** | **No.**  | **%**  |
| Accessibility needed for all / fairer  | 9 | 20%  |
| Will result in improvements to patients’ quality of life  | 9 | 20%  |
| Support that patients need to have demonstrated own effort / exhausted all other avenues  | 4 | 9% |
| Cost effective / will reduce the need for longer-term medial costs  | 4 | 9% |
| Support commitment to long-term follow up  | 3 | 7% |
| **Objections / further considerations**  | **No.** | **%** |
| Importance of counselling / support pre- and post-operatively | 7 | 16% |
| Disagreement with threshold criteria  | 7 | 16% |
| Disagreement that NHS funding should be allocated to this / feeling that patients need to try other things to lose weight  | 6 | 13% |
| **Other comments**  | **No.** | **%** |
| Other, including: Support if medical reasons Should be considered on case-by-case basis Comment about personal experience  | 4 | 9% |
| Not sure  | 1 | 2% |

*\*Due to the free text nature of this question, percentages do not equate to 100%.*

### Clinical service - breast asymmetry

This section of the survey was completed by 30 individuals. Overall, 50% strongly support and 17% support the proposed policy update for breast asymmetry. In contrast, 26% oppose these changes to some extent. These respondents were from:

* Brentwood Borough Council (N=2; 11%\*)
* Chelmsford City Council (N=2; 6%\*)
* Castle Point Borough Council (N=2; 15%\*),
* Basildon Borough Council (N=1; 2%\*)
* Southend-on-Sea City Council (N=1; 3%\*).

*\*Percentages shown as a proportion of respondents from this area.*

Q To what extent do you support or oppose the proposed policy update? (N=30)

|  |  |  |
| --- | --- | --- |
| **Support or oppose** | **No.**  | **%**  |
| Strongly support  | 15 | 50% |
| Support  | 5 | 17% |
| Neither support/oppose  | 2 | 7% |
| Oppose  | 4 | 13% |
| Strongly oppose  | 4 | 13% |

*Figure 3 To what extent do you support or oppose the proposed policy update? (N=30)*

In support of the proposed policy update, respondents noted how this will help to improve the physical and mental health of patients that require this type of surgery and ensure fairness / equitable access for all residents across the region.

“All residents should access to the same service. It should not be a postcode lottery”

“Treatment to prevent preventable anxiety is justified”

In contrast, for those that opposed the update or felt that further thought was needed, concern was raised about the threshold criteria, in terms of:

* It being too high.
* The difficulty of providing evidence of serious functional impairment for at least one year.
* The omission of gynecomastia (enlarged male breasts).
* Care being denied to smokers, with no mention of drug / alcohol use.
* Two cup sizes of difference not being significant enough to have huge impact on physical health.

“I would like to know why the patient must be a non-smoker, but no alcohol and no drugs are not mentioned? Also, why gynecomastia is not covered?”

It was additionally felt by a few, that in some cases, augmentation of the smaller breast must also be made.

“I do think in some cases augmentation of the smaller breast should be considered, depending on the person’s body and other factors.”

Other comments were made around the surgery being seen as cosmetic, with feeling that this should not be funded by the NHS.

“This surgery should not be NHS funded unless there is a SERIOUS risk to health and the patient has been means-tested to rule out the possibility of private treatment”

Q: Please explain your response (N=28)\*

|  |  |  |
| --- | --- | --- |
| **Support / positive comments** | **No.**  | **%**  |
| Will result in improvement to patients’ physical and mental health  | 9 | 43% |
| Fair and accessible for all  | 2 | 7% |
| **Objections / further considerations**  | **No.** | **%** |
| Disagreement with the threshold criteria | 6 | 21% |
| Seen as cosmetic / disagreement with NHS funding being used this way  | 5 | 18% |
| Breast augmentation must also be considered  | 3 | 11% |
| **Other comments**  | **No.** | **%** |
| Other, including: Should be limited access for this Should be decided on case-by-case basis and only undertaken if other measures have been attempted first | 2 | 7%  |

*\*Due to the free text nature of this question, percentages do not equate to 100%.*

### Clinical service - breast reduction

This section of the survey was completed by 42 individuals. Overall, 38% strongly support and 31% support the proposed policy update for breast reduction. In contrast, 24% oppose this change to some extent. The latter included individuals from:

* Chelmsford City Council (N=3; 9%\*)
* Brentwood Borough Council (N=2; 11%\*)
* Basildon Borough Council (N=2; 4%\*)
* Maldon District Councill (N=1; 9%\*)
* Southend-on-Sea City Council (N=1; 3%\*)
* Castle Point Borough Council (N=1; 8%\*)

*\*Percentages shown as a proportion of respondents from this area.*

Q To what extent do you support or oppose the proposed policy update? (N=42)

|  |  |  |
| --- | --- | --- |
| **Support or oppose** | **No.**  | **%**  |
| Strongly support  | 16 | 38% |
| Support  | 13 | 31% |
| Neither support/oppose  | 3 | 7% |
| Oppose  | 6 | 14% |
| Strongly oppose  | 4 | 10% |

*Figure 4 To what extent do you support or oppose the proposed policy update? (N=42)*

In support of the proposed policy update, respondents indicated their agreement with the criteria and how it provides fairness and accessibility for all. Furthermore, others talked of the physical and mental health benefits that this would bring to patients, as well as the reduction in associated costs for the NHS.

“Quality of life for those who have larger breasts and constant pain and rubbing”

“As something that can cause both physical severe back pain, and affect mental health, it would benefit many people for care to be provided on the NHS”

Others felt the proposed policy changes would be acceptable if a clinical need is proven and/or if other interventions such as diet and exercise, haven’t worked.

“I would support if the clinical evidence of significant pain could be provided, and that pain was impacting on day-to-day life. If not, as with the previous service area, this falls under the banner of cosmetic surgery and should not be funded by the NHS”

“This procedure should not be NHS funded unless a SERIOUS risk to health and the patient has been means-tested to rule out the possibility of private procedure”

For those that opposed the update or felt that further consideration was needed, concern was raised about the use of BMI as an indicator. More specifically, BMI was described as being ‘irrelevant’ and ‘old-fashioned’, failing to consider muscle mass and the weight of the breasts.

“I support that this is offered however I think considerations need to be made, especially with regards to BMI. Someone with very large breasts will show up as a higher BMI due to their weight, which may skew results.”

Further disagreement / comment was made about the threshold criteria in terms of:

* It being too high e.g., a patient needs to suffer from persistent intertrigo (a rash caused by skin-to-skin rubbing) for at least a year (or other serious functional impairment) before they are allowed surgery.
* BMI level should be increased / decreased.
* Suggested alternative criterion around the lifestyle the patient wishes to live.
* Omission of non-smokers but no consideration of alcohol / drug use.
* Current 500g considered a better criterion.

“There needs to be an alternative criterion around the lifestyle the patient wishes to live. For example: a) the patient is struggling to exercise due to breast pain despite using a supportive sports bra and boob buddy. b) the patient used to partake in certain activities/sports but due to breast growth (either following puberty or pregnancy) has found this more difficult.”

Additionally, breast reduction was viewed by others as a type of cosmetic surgery, and/or not something that should be funded by the NHS.

Q Please explain your response (N=40)\*

|  |  |  |
| --- | --- | --- |
| **Support / positive comments** | **No.**  | **%**  |
| Agree with criteria and fairness / accessibility for all  | 12 | 30% |
| Physical / mental health benefits (and associated costs for NHS)  | 6 | 15% |
| Acceptable if clinical need proven  | 3 | 8% |
| Acceptable if other interventions haven’t worked  | 1 | 3% |
| **Objections / further considerations**  | **No.**  | **%**  |
| Concern of accuracy of BMI as an indicator | 11 | 28% |
| Disagreement with threshold criteria  | 8 | 20% |
| Seen as cosmetic / do not agree with NHS funding being used in this way | 6 | 15% |
| **Other comments**  | **No.**  | **%**  |
| Comment about personal experience  | 1 | 3% |

*\*Due to the free text nature of this question, percentages do not equate to 100%.*

### Clinical service - female sterilisation

This section of the survey was completed by 32 individuals. Overall, 44% strongly support and 19% support the proposed policy update for female sterilisation. In contrast, 25% oppose this change to some extent. This included individuals from:

* Castle Point Borough Council (N=2; 15%\*)
* Brentwood Borough Council (N=2; 11%\*)
* Basildon Borough Council (N=1; 2%\*)
* Maldon District Council (N=1; 9%\*)
* Rochford District Council (N=1; 14%\*)
* Chelmsford City Council (N=1; 3%\*)

*\*Percentages shown as a proportion of respondents from this area.*

Q To what extent do you support or oppose the proposed policy update? (N=32)

|  |  |  |
| --- | --- | --- |
| **Support or oppose** | **No.**  | **%**  |
| Strongly support  | 14 | 44% |
| Support  | 6 | 19% |
| Neither support/oppose  | 4 | 13% |
| Oppose  | 3 | 9% |
| Strongly oppose  | 5 | 16% |

*Figure 5 To what extent do you support or oppose the proposed policy update? (N=32)*

In support of the proposed policy update, respondents indicated their agreement with the criteria and how it enables fair access for all. Furthermore, others agreed with women’s rights to choose this as a form of contraception.

“These policy updates will bring equality”

“Everyone should have a choice on their body.”

In contrast, for those that opposed the update or felt that further thought was needed, concern was raised about the threshold criteria, in terms of:

* The BMI level being too high / patients being penalised for being overweight.
* BMI not being an accurate indicator of weight.
* Approval should be individual (not group).
* Disagreement with the criterion around Long-Acting Reversible Contraception (LARC) and patients having to have ‘severe side effects’.
* Issue with criterion around capacity of patients.
* Feeling that there should be no caveats to a woman making decisions regarding her own body (i.e., counselling, consideration of vasectomy) / inequality with threshold criteria for vasectomy.
* Feeling that an additional exemption is required for women who are having to do this surgery without consultation with their partners (i.e., due to religious / cultural issues).

“I disagree about BMI limit, there are many reasons for increased BMI and in fact surely getting pregnant makes it a high risk one by default of mum is bigger. I also disagree that you aren't putting the same restrictions on male vasectomy.”

“I oppose this due to the restrictions around LARC. What is considered ‘severe side effects’? LARC, whilst reliable, are not found to be suitable by many women. Also, what is being put in place for women with a BMI of over 35?”

Furthermore, others felt that NHS funding should not be used in this way and/or female sterilisation is not a medical matter.

“There are alternative, less permanent measures that can be utilised. I have a real issue with this for patients who lack capacity. This should not be funded by the NHS although note likely to effect very small numbers of patients.”

Q Please explain your response (N=30)\*

|  |  |  |
| --- | --- | --- |
| **Support / positive comments** | **No.**  | **%**  |
| Agree with criteria and accessibility for all / fairer  | 8 | 27% |
| Agree with women’s rights to choose this as a form of contraception  | 7 | 23% |
| Support for statement around capacity  | 2 | 7% |
| **Objections / further considerations**  | **No.**  | **%**  |
| Disagreement with threshold criteria | 8 | 27% |
| Do not agree with funding being used in this way / not a medical matter  | 5 | 17% |
| Objection: Relationships can fail with unfortunate consequences for future relationships for the other partnerOppose when used as a personal / lifestyle choice | 2 | 7%  |
| **Other comments**  | **No.**  | **%**  |
| Other comment, including: Concern as to whether doctors will have the correct conversations with patientsMore information needed | 3 | 10%  |

*\*Due to the free text nature of this question, percentages do not equate to 100%.*

### Clinical service - vasectomy

This section of the survey was completed by 32 individuals. Overall, 56% strongly support and 16% support the proposed policy update for vasectomy. In contrast, 15% oppose this change to some extent. The latter included individuals from:

* Brentwood Borough Council (N=1; 5%\*)
* Basildon Borough Council (N=1; 2%\*)
* Castle Point Borough Council (N=1; 8%\*)
* Southend-on-Sea City Council (N=1; 3%\*)
* Chelmsford City Council (N=1; 3%\*)

*\*Percentages shown as a proportion of respondents from this area.*

Q To what extent do you support or oppose the proposed policy update? (N=32)

|  |  |  |
| --- | --- | --- |
| **Support or oppose** | **No.**  | **%**  |
| Strongly support  | 18 | 56% |
| Support  | 5 | 16% |
| Neither support/oppose  | 4 | 13% |
| Oppose  | 2 | 6% |
| Strongly oppose  | 3 | 9% |

*Figure 6 To what extent do you support or oppose the proposed policy update? (N=32)*

It was felt that the proposed policy update would make access fairer for all, with the current policy perceiving to go against the idea of gender-equitable family planning and acting as a ‘postcode lottery’ for residents.

“These services should be available to all across Mid and South Essex”

“All residents should access to the same service. It should not be a postcode lottery”

Others highlighted how vasectomy is a vital part of family planning, which allows men to take greater responsibility, and for some is a ‘better option’ than the female using contraceptives or undergoing sterilisation.

“My husband has been unable to access a vasectomy despite us having 5 children and not wanting to have anymore. I find it absurd that the funding is available for contraceptives for myself which have a detrimental effect on my health but there is no funding for a procedure that will have no negative effects on either of us.”

For those that opposed the update or felt that further thought was needed, there was a feeling amongst some that NHS funding should not be used in this way.

“Once again can we really afford to give this treatment. Surely there are other more critical conditions that need the funding.”

Several points for consideration were also raised with regards to the threshold criteria. These included:

* Referral for general anaesthetic should be individual approval, not group.
* Lack of consideration for those who may choose to have a general anaesthetic.
* Lack of mention of smoking / drugs / alcohol.

“Not considered ‘why a patient might choose to want to have general’ - anxiety? mental health issues? Should also be flexible to meet needs of people that may need support as above or if have disabilities with sensory issues.”

A small number additionally considered it unfair how men do not have to undergo the same counselling processes as females pursuing sterilisation, with feeling that the criterion around this should be comparable.

“My husband has had a vasectomy and was subject to none of the counselling etc required for female sterilisation. This points to strong inequality in how men and women are considered to have ownership of this decision.”

Q Please explain your response (N=30)\*

|  |  |  |
| --- | --- | --- |
| **Support / positive comments**  | **No.**  | **%**  |
| Agree with criteria and accessibility for all / fairer  | 11 | 37% |
| Allows men to have greater responsibility / better option for men to be sterilised  | 3 | 10% |
| **Objections / further considerations**  | **No.**  | **%**  |
| Do not agree with NHS funding being used in this way / not a medical matter  | 5 | 17% |
| Disagreement with the threshold criteria | 4 | 13% |
| Criteria should replicate that of female sterilisation i.e., counselling | 2 | 7% |
| **Other comments**  | **No.**  | **%**  |
| Other comment, including: Personal experience – not able to afford privately Local anaesthetic appropriate here | 4 | 13%  |

*\*Due to the free text nature of this question, percentages do not equate to 100%.*

### Clinical service - special fertility services

This section of the survey was completed by 154 individuals. Overall, 52% strongly support and 26% support the proposed policy update for special fertility services, whilst 2% neither oppose or support and 20% oppose it to some extent. The latter included individuals from:

* Southend-on-Sea City Council (N=5; 17%\*)
* Chelmsford City Council (N=5; 15%\*)
* Braintree District Council (N=4; 16%\*)
* Brentwood Borough Council (N=4; 21%\*)
* Basildon Borough Council (N=4; 8%\*)
* Maldon District Council (N=4; 36%\*)
* Rochford District Council (N=2; 29%\*)
* Thurrock Council (N=1; 7%\*)
* Other (N=1; 10%\*)

*\*Percentages shown as a proportion of respondents from this area.*

Q To what extent do you support or oppose the proposed policy update? (N=154)

|  |  |  |
| --- | --- | --- |
| **Support or oppose** | **No.**  | **%**  |
| Strongly support  | 80 | 52% |
| Support  | 40 | 26% |
| Neither support/oppose  | 3 | 2% |
| Oppose  | 16 | 10% |
| Strongly oppose  | 15 | 10% |

*Figure 7 To what extent do you support or oppose the proposed policy update? (N=154)*

When asked to elaborate on their response, respondents expressed their agreement in providing equitable access for all residents and further providing greater opportunity for childless couples to have children.

“You pulled funding one year before my husband and I were told we required ICSI to conceive. Quite devastating for us. Although this policy change is too late for us, hopefully other couples will be helped!”

“I have a very close friend who lives in Braintree and is currently having to pay thousands for IVF as no funded cycles are offered to her. She is going into debt to do this as her and her partner have been trying for over 10 years. It’s heart-breaking to see them go through this and it would mean so, so much if they received NHS funding.”

“I feel everyone has the right to have children should they wish to and currently in the area it is only available to those who can conceive naturally or can afford to go privately. This has put extra stress and pressure on myself and my husband to try and save for private treatment especially in today’s economic crisis.”

Others indicated how this policy currently affects them, or a member of their family, having been denied access to treatment and/or not being able to afford treatment privately.

“My partner and I tried for 2 years to have a baby without success. I am 35 years old and I am very concerned that I might need IVF and we won't be able to afford this without NHS funding.”

For those that opposed the update or felt that further thought was needed, disagreement with certain aspects of the threshold criteria was expressed. This included:

* Criterion around no living children in the current relationship / neither partner has children from previous relationships.
* Criterion around previously privately funded IVF cycles being considered within the total number of cycles offered by the ICB.
* Criterion around same sex couples having to have had six cycles of privately funded IUI.
* Age restriction of 40.
* Couples having to have a two-year period of infertility (suggestion that this should be less / one year).
* BMI being included as a criterion.

It was felt by these respondents that there is opportunity for the criteria to be more inclusive and provide more equitable access for same sex couples, single parents, blended families, and those who have accessed treatment privately.

“Privately funded prior IVF cycles should not count towards your entitlement.”

“Appears unfair on same sex couples and people with children.”

Further consideration was also felt to be needed in terms of the mental health support provided to couples throughout their journey, the number of IVF cycles offered and/or access for those who have experienced medical conditions earlier in life which have affected their fertility e.g., testicular cancer.

“It’s a very overwhelming and emotional time for many, and there is not really any additional support or anyone to reach out to in this process.”

“I have suffered with testicular cancer twice and am unable to have a baby naturally I therefore think I should be eligible for IVF.”

Those who strongly objected to the proposed policy update felt that this is not a service that should be funded by the NHS.

Q Please explain your response (N=142)\*

|  |  |  |
| --- | --- | --- |
| **Support / positive comments** | **No.** | **%** |
| Agree with accessibility for all / access shouldn’t be a postcode lottery / important to ensure equality and fairness | 70 | 49% |
| Affects my family / currently been denied / can’t afford privately | 5 | 4% |
| **Objections / further considerations** | **No.** | **%** |
| Disagreement with criterion re: no living children in the current relationship / neither partner has children from previous relationships  | 17 | 12% |
| Concerns about costs to the NHS / feeling that this is a non-essential service which should be privately funded | 17 | 12% |
| Disagreement with criterion re: previously privately funded IVF cycles being considered within the total number of cycles offered by the ICB | 12 | 8% |
| Disagreement with criterion re: same sex couples having to have had six cycles of privately funded IUI | 9 | 6% |
| Mental health implications  | 8 | 6% |
| Two cycles of IVF is not sufficient / greater number required | 7 | 5% |
| Disagreement with criterion – other, including: -        Not inclusive enough-        No mention of single parents-        Full IVF cycle should include one egg collection and one fresh and frozen transfer  | 7 | 5% |
| Disagreement with BMI being used as a criterion | 5 | 4% |
| Disagreement with age restriction of 40 | 5 | 4% |
| Disagreement with couples having to have a two-year period of infertility | 4 | 3% |
| Consider support for those whose previous medical conditions have affected their fertility   | 3 | 2% |
| **Other comments** | **No.** | **%** |
| Other comments | 5 | 4% |

*\*Due to the free text nature of this question, percentages do not equate to 100%.*

### Proposed policy update (general)

Survey respondents were given the option to select the clinical service areas that they wished to provide their views for or comment on the proposed policy update generally.

This section of the survey was completed by 12 individuals. Whilst six individuals either strongly supported or supported the policy update, four individuals oppose / strongly oppose them. Those in agreement felt the policy update would provide equitable access and promote fairness across the region.

“I believe that all patients should have the same choices since we have become one trust, but we still need to look at a patient as an individual”

“Provision of NHS services should be harmonised nationally, there should be no difference in provision based on location.”

Those who oppose the policy update, felt strongly that NHS funding should not be used to provide these clinical services.

“With the NHS costing some £150 billion p.a. these types of services should be funded by the individual recipient.”

“Concentrate on providing basic medical care i.e., hip/knee replacement, doctor appointments etc. Breast enlargement, reduction and alignment are vanity / cosmetic procedures and should be in the private sector.”

Q To what extent do you support or oppose the proposed policy update? (N=12)

|  |  |  |
| --- | --- | --- |
| **Support or oppose** | **No.**  | **%**  |
| Strongly support  | 2 | 17% |
| Support  | 4 | 33% |
| Neither support/oppose  | 2 | 17% |
| Oppose  | 1 | 8% |
| Strongly oppose  | 3 | 25% |

*Figure 8 To what extent do you support or oppose the proposed policy update? (N=12)*

Q Please explain your response (N=12)\*

|  |  |  |
| --- | --- | --- |
| **Comment** | **No.**  | **%**  |
| Generally, in favour / agree with improving fairness and accessibility  | 7 | 58% |
| Should not be funded by NHS  | 3 | 25% |
| Other comment, including: More information needed about full funding Each patient must be looked at individually  | 4 | 33% |

*\*Due to the free text nature of this question, percentages do not equate to 100%.*

### Reviewing services (general)

In terms of reviewing these services, respondents were asked what they felt was important to them. The range of responses provided are shown in the table below with most commenting upon the importance of ensuring equitable access to these clinical services for all.

“For better equality for patients.”

“That all individuals are fairly treated despite relationship status, gender identity and sexuality.”

Furthermore, many comments were specifically made about the importance of providing equitable access to special fertility services, as well as disagreement / frustration with aspects of the proposed threshold criteria for this clinical service.

“Everyone gets the chance of having a child. It shouldn’t matter that your postcode isn’t right.”

“That all areas should be entitled to the same number of rounds and have the same criteria to qualify. Infertility is hard enough without having to worry about whether you are entitled to help or not and having to jump through endless hoops to get there.”

Specific comments about equality in access / the threshold criteria for the other clinical areas were also made, but to a lesser extent.

“For vasectomies to be funded fairly across Essex irrespective of district.”

“That you do not focus on obesity as being a disease that is self-inflicted because someone has eaten too many calories and is not exercising.”

Others felt it was important to consider the financial implications and ensuring best use of resources, the importance of patients’ input, choice and communication, the mental and physical health implications and/or the time it will take to implement these changes.

“That NHS money is spent wisely on getting the waiting lists down for people who need medical care.”

“That there are not too many barriers, mental health appears not to be mentioned much.”

Comments were also made by some of the need to prioritise other ‘essential’ or ‘basic’ services such as primary care and access to GP appointments, cancer and other health conditions that seriously affect the quality of life of individuals such as chronic pain and joint replacements.

“NHS is spending money on "luxury" services whilst failing to meet the needs of basic services.”

“With reference to breast asymmetry, breast reductions and fertility treatment, unless any of these procedures are life-saving or represent value for money from future costs involved in NOT giving these procedures, they should be self-funded.”

Q: What is important to you as we review these services? (N=191)\*

|  |  |  |
| --- | --- | --- |
| **Comment** | **No.** | **%** |
| Accessibility and equality for all  | 69 | 36% |
| Service harmonisation / fairness – special fertility services  | 57 | 30% |
| Financial considerations / ensuring best use of resources  | 14 | 7% |
| Priority should be placed on essential services – cited clinical services should not be available on the NHS  | 14 | 7% |
| Importance of patients’ input, choice, and communication  | 12 | 6% |
| Consideration of mental and physical health implications  | 10 | 5% |
| Waiting times / implementation of changes  | 7 | 4% |
| Service harmonisation / fairness – bariatric surgery  | 5 | 3% |
| Service harmonisation / fairness – vasectomy  | 3 | 2% |
| Everything / all valuable services  | 2 | 1% |
| Service harmonisation / fairness – breast reduction  | 2 | 1% |
| Other, including: If treatment to be paid for, make it affordable Systems should not be burdensome to clinicians nor divert from patient care | 16 | 8% |

*\*Due to the free text nature of this question, percentages do not equate to 100%.*

### Additional paper response received

A late paper response to the consultation was received from an individual residing within Thurrock Council. This individual indicated that they might be affected by this policy in the future.

The individual was aged 65-74, White British and identified as a heterosexual woman. They stated having a physical or mental health condition / illness lasting or expected to last 12 months or more, and how this impacts a little on their day-to-day activities. In terms of financial status, they stated that they have more than enough money for basic necessities and a little spare that they can save or spend on extras or leisure’.

Their views on the different clinical areas are captured here.

**Bariatric surgery -** support

The respondent noted how the run up to this type of surgery would be intense and stressful for patients, with regard to the weight loss criterion.

**Breast asymmetry -** neither support nor oppose

The respondent is not affected by this policy but understands how stressful this would be for individuals going through this.

**Breast reduction -** strongly support

The respondent has seen the impact of this problem and believes it is necessary.

**Female sterilisation** - strongly support

The respondent agrees that women should have the right to choose but feels the pre-surgery programme should be ‘correctly geared up for ease of use when people are completely sure of using this option’.

**Vasectomy -** strongly support

The respondent feels that people should have the right to choose this and that this is effective in supporting population control.

**IVF -** neither support nor oppose

The respondent stated how this is a tough progress to go through ‘in any version’.

Overall, the respondent felt it would be good to have the same policies covering Mid and South Essex.

## Feedback from the public events and focus groups

The following summarises the feedback from the public events and focus groups, in which twenty individuals were engaged with.

Some individuals had specific experience of the clinical areas - vasectomy, special fertility services, female sterilisation, and bariatric surgery.

Equality monitoring data collected from the individuals who attended the public events can be found in Section 3.3.

Table 1 Public events and focus groups

|  |  |  |
| --- | --- | --- |
| **Public events dates**  | **Location** | **No. of attendees** |
| 9th November 2022 | Greys  | 0 |
| 10th November 2022  | Witham  | 1 |
| 22nd November 2022  | Basildon  | 1 |
| 24th November 2022  | Southend  | 0 |
| 30th November 2022  | Online  | 5 |

|  |  |  |
| --- | --- | --- |
| **Focus groups**  | **Detail**  | **No. of attendees** |
| 21st November 2022  | Microsoft Teams conversation  | 1 |
| 22nd November 2022 | Online Men’s Focus Group  | 10  |
| 15th December 2022 | Bariatric Focus Group  | 1 |
| 15th December 2022 | LGBT Mummies Group  | 1\* |
| **Total**  |  | **20** |

*\*Participant presented collated feedback on behalf of the group.*

Overall, attendees were generally supportive of the proposed policy update. However, several queries and points for further considerations were raised generally, as well as specifically for the different clinical services. The greatest challenges were raised about special fertility services.

### Proposed policy update – general comments / queries

Comments / queries raised about the policy update in general, included:

* What has the reaction been to the proposals so far? Has there been any feedback that has made you rethink?
* What are the financial implications of making these changes, and will this impact on the delivery of other services?
* Should every policy reflect co-morbidities?
* Are there plans to harmonise any other services across MSE? E.g., micro suction (ear syringing) considering the evidence that links this with cognitive ability / Alzheimer’s Disease.
* What are the implications for the wider ICS area?

Further consideration was felt to be needed with regards to:

* The impact that these policies / health areas have on patients’ mental health, as well as that of their partners and families.
* Communication of these policy changes among primary care colleagues.

### Clinical service - bariatric surgery

One individual discussed their personal experience of bariatric surgery. Following a personal tragedy, this individual described how their weight gain ‘went out of control’. Despite successful attempts at losing weight, the individual was never able to maintain their weight loss. The individual described how their weight not only affected their physical health but their mental health and wellbeing.

The individual was referred for surgery by their GP and informed of an expectation to lose 10% of their excess weight. This caused concern for the individual as they were worried that losing the weight whilst waiting for surgery, might ‘go against them’.

Once accepted for surgery, the individual discussed the difficulties and frustrations they faced in terms attending their pre-operative appointments, with all of these being undertaken at a hospital in London (Homerton).

“If you miss an appointment or don’t turn up, you’re incidentally struck off.  But the service cancelled without any prior notice which is really frustrating especially when you’ve taken time off work and bought travel tickets.”

The individual was therefore supportive of the proposed policy update and having services closer to home.

“Everything needed to be done at Homerton – ECG, blood tests, they could have been done closer to home.”

The importance of providing care closer to home was reinforced by individuals from the Bariatric Support Group who also stressed the difficulties they faced travelling to London for tests / procedures, particularly when there was a requirement for them to be accompanied.

“Only really need to go to Homerton to see surgeon and have op everything else could have been done locally.”

Despite pre-operative psychiatric assessments, the individual who shared their experience noted how they were not prepared for the changes to their body shape that would result from the surgery and the impact that this would have on her mental health and confidence. Although feeling in good physical health, their excess skin has led to sores and depression, affecting their ability to form personal relationships.

When considering the policy updates for bariatric surgery, several considerations were therefore raised:

* The need for greater flexibility for accessing the local weight management pathway / services e.g., appointment times to cater for those in full-time employment and/or with children.
* Ability for patients to access local services for pre-operative appointments / assessments to avoid them having to travel to London / Homerton.
* Provision of surgery to remove excess skin, and for this not to be viewed as a cosmetic procedure.

### Clinical service - breast reduction

One individual, who lives in Witham, discussed their personal experience of seeking breast reduction surgery. Over the last nine years, this individual has requested surgery four times and was advised, during her latest consultation with her GP in 2022, that she would be referred but it would likely be rejected. The individual has sought advice privately but the cost of £7,000 for the surgery makes it inaccessible.

The individual discussed the negative impact that her condition has on her mental health.

Although the individual supports the proposed policy update and the funding that will now be available for patients in Mid Essex, she expressed concern that the threshold criteria will restrict and discriminate against some. It was therefore felt that greater flexibility is needed when considering the specific needs of each patient, including size / frame, mental health, neurodiversity, and the impact on existing health issues such as hiatus hernia and/or asthma.

“All of these [clinical areas] do need a process of some sort to balance but they do not reflect the individual. Everyone should get a fair trial and not try to be fixed into a box.”

Additionally, it was noted how ‘going without a bra’ is not an option for some women with large breasts, and therefore the criterion around skin rashes is not applicable, and furthermore how there should be an option for part payment or income-based test to fund treatment.

Another individual additionally highlighted the importance of taking patients’ mental and physical wellbeing into account, with it further questioned whether the changes would mean fewer people will qualify for the service.

### Clinical service – vasectomy

The participants in the online men’s focus group supported the proposed policy update for this clinical area.

### Clinical service - female sterilisation

It was queried as to what will happen in circumstances where one partner wants to be sterilised, but their partner doesn’t want them to have the procedure.

### Clinical service - special fertility services

Special fertility services were discussed by a small number with experience of accessing these services through the NHS and privately. This included a representative from LGBT Mummies Group and from the MSE Maternity and Neonatal Voices Partnership. The discussion with this representative was also recorded in a letter they sent after the discussion and this report draws on the record of the discussion and the letter.

Several concerns about the policy update were raised by these individuals, which would result in potential areas of inequalities and discrimination. It was therefore strongly felt that these need to be considered to help avoid further implications, including legal action.

“I would strongly suggest you reconsider the provision you have put forward and undertake a more in-depth review, to result in a more inclusive and fair approach, and to negate additional cost, legal issues and possible reputational risk which could lead to MSE being vilified in the press, and those communities being discriminated against seeking legal action on MSE.”

A summary of these issues / concerns is documented here:

* Concern was raised about the impact that the policy update will have on those who have self-funded IVF in the past, with it was questioned as to how this will be policed and what it will mean for those who have gone abroad for treatment. It was suggested that couples who have sought private provision in the past should be disregarded so that they can still access NHS service provision.

“If I wasn’t pregnant now, I would still be unable to access IVF as I’ve had to go private as there were no other options for me and my partner for the past 7 years. This is unfair because if I had had an MRI privately and needed further MRI/treatment this would be possible. This does not happen for any other service access.”

If this criterion is to remain, the importance of managing communications around these changes was stressed.

* With current statistics showing that between 42-48% of parents are divorced, the policy update was felt to discriminate against infertile couples with children from previous relationships impacting on eligibility.
* The update was recognised to omit trans and non-binary people.
* The lack of access for single people and gay dads was felt to be discriminatory, although recognised as an issue that sits with NICE guidance.
* There was concern that the update which removes IUI funding completely does not follow national guidance as outlined in the Women’s Health Strategy, and directly impacts on those requiring sperm donation.

Furthermore, the implications for those who have better fertility and may wish to have something less invasive, as well as those who may have medical conditions, meaning they can’t undergo IVF, or are victims of domestic / sexual abuse who may not wish to have IVF due to how traumatic it could be, were discussed. Although IUI may have a lower success rate than IVF, it was noted how the procedure is less invasive, more cost effective and can be provided to any couple who in many cases may just need support with timing and some additional medical intervention to support a pregnancy.

“In my case we require donor sperm due to male factor infertility. The offering is for two rounds of IVF, yet I understood it’s one vial of donor sperm. It sounds as though it means that someone in my circumstance would be directly impacted and not able to obtain the second round?”

* It was questioned why reciprocal IVF is not included, despite current laws that the UK are governed by stating that the partner of a same sex couple undergoing egg collection within a reciprocal IVF cycle is screened, tested and legally viewed as a ‘Donor’ of the egg.

“…therefore, if viewed as a Donor by law, why would MSE not provide same sex couples with the opportunity to have Reciprocal IVF as part of their funding? The ‘Donor’ of the egg may be part of the coupling, but by law are viewed as a Donor, therefore should also have access to egg donation - therefore Reciprocal IVF should then be offered. If not, then this would appear discriminatory based on sexual orientation, and we know this will create further division and shine a spotlight on MSE as a discriminatory Trust.”

* In terms of embryos, questions were asked as to:
	+ where these will be stored?
	+ who claims of ownership of them?
	+ who takes care of the cost while treatment is commencing, and once a pregnancy results who then incurs that cost? Furthermore, if no pregnancy happens, who pays for them to be stored?
* The proposal of two rounds of funded IVF for those aged 23-39 years and then one round for those aged 40-42 was noted to ‘still fall short’ of the national guidelines of three rounds. Furthermore, it was felt to make no logical sense with evidence suggesting that those of advanced maternal age are at greater risk of lower pregnancy outcomes. To avoid age discrimination, it was suggested that the older age group should have equal access, if not greater access to improve success.
* There was concern that the proposed one sperm vial per round might cause implications should someone only create one embryo in one round.

“… therefore you as a Trust would have to purchase more sperm for the next attempt, the donor could retire, be bought up and no longer be available, and the couple would then have to find a new donor,  and could cause serious delays, which could result in them not then meeting the criteria to access funding moving forward and the possibility of them being able to privately purchase additional vials for further siblings not be viable either - something Donor Conceived children stress is vital for them to be genetically related to their siblings if possible.”

* In offering fertility treatment to those of advanced maternal age, it is felt that genetic testing must be considered to ensure embryos transferred are not abnormal. It was noted that by not offering this, there will be very real human implications and the cost of which to the NHS in support, care, time, salaries will by far exceed the cost of the testing, should MSE provide the testing.
* The BMI guidance of 30 and under was felt to be discriminatory against larger bodied women and people who wish to start a family but are being stopped due to their size. Furthermore, it was noted how certain health conditions such as endometriosis, prevent individuals from losing weight.

“They are being denied the funding to start their family, yet others who can try naturally, are not stopped from doing so? We are acutely aware that being of a larger BMI can impact & increase the risk of miscarriage & loss, however a further discussion is needed on this subject.”

* Although the inclusion of same sex couples was felt to be a positive, it is argued that the vision for same sex couples to have to undergo up to six privately funded rounds of fertility treatment before being considered by MSE for fertility funding goes against the changes that have been brought in through the Women’s Health Strategy, which addresses the inequalities and discriminatory access for same sex couples.
* Under the new proposals, some patients who weren’t eligible for IVF treatment will now be. There is concern that if the proposals don’t go ahead, the hopes of these patients will be dashed.

“I am pleased that this could happen for us. But what if the proposals don’t go through and I’m not eligible, I’ll feel let down and it’s tough to mentally deal with that chance to be taken away again.”

* Recognising the lack of mental health support provided to individuals on their fertility journey, it was felt imperative that this is considered, in addition to providing support to those who are not eligible to receive fertility treatment.

“If you were given a cancer diagnosis you would get a McMillian [sic] leaflet and signposting.”

“Two rounds is very positive, but signposting is needed if there is negative news.”

* Questions were asked as to how MSE will prioritise who gets access first and whether this will this be based on time entering the system or by need? Furthermore, it was asked as to whether individuals from the two areas who haven’t been able to access special fertility services will be fast tracked for treatment.

“Two areas that haven’t has access to services for years need to be able to access quicker.”

* It was suggested that the proposals should consider surrogacy as an option.
* It is thought that the longer-term care implications for IVF patients must be considered, as patients receiving this type of treatment need more care / appointments with babies often needing longer-term care.
* It is thought that training is required for doctors and hospital staff to help improve knowledge and confidence, including greater awareness of genetic conditions that affect fertility.
* There was felt to be a lack of focus on male fertility within the document.
* It is thought that the terminology used in the document is confusing.

## Equality and monitoring data for survey respondents / public event attendees

Survey respondents (N=210)

Public event attendees (N=7)

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Age**  | **No.**  | **%**  | **No.**  | **%**  |
| 16 to 24 | 1 | 0% | - | - |
| 25 to 34 | 64 | 30% | 1 | 14% |
| 35 to 34 | 55 | 26% | 2 | 29% |
| 45 to 54 | 26 | 12% | - | - |
| 55 to 64 | 24 | 11% | - | - |
| 65 to 74  | 17 | 8% | 1 | 14% |
| 75 to 84  | 4 | 2% | - | - |
| 85 and over  | 0 | 0% | - | - |
| Prefer not to say  | 20 | 9% | 3 | 43% |
| **Currently pregnant / been pregnant in last year** | **No.**  | **%**  | **No.**  | **%**  |
| Yes | 29 | 14% | - | - |
| No | 138 | 65% | 4 | 57% |
| Not applicable | 20 | 9% | - | - |
| Prefer not to say  | 24 | 11% | 3 | 43% |
| **Ethnic group or background**  | **No.**  | **%**  | **No.**  | **%**  |
| White - English, Welsh, Scottish, Northern Irish or British  | 173 | 82% | 3 | 43% |
| White - Irish  | 2 | 1% | - | - |
| Mixed or multiple ethnic groups - White and Black African  | 1 | 0% | - | - |
| Mixed or multiple ethnic groups - White and Asian  | 1 | 0% | - | - |
| Asian or British Asian - Indian  | 2 | 1% | - | - |
| Asian or British Asian - Pakistani  | 1 | 0% | - | - |
| Asian or British Asian - Chinese  | 1 | 0% | - | - |
| Black, Black British Caribbean or African - Caribbean  | - | - | 1 | 14% |
| Black, Black British Caribbean or African - African  | 3 | 1% | - | - |
| Arab  | 1 | 0% | - | - |
| Other  | 4 | 2% | - | - |
| Prefer not to say  | 22 | 10% | 3 | 43% |
| **Sexual orientation**  | **No.**  | **%**  | **No.**  | **%**  |
| Heterosexual or straight  | 175 | 83% | 4 | 57% |
| Bisexual  | 8 | 4% | - | - |
| Gay or lesbian  | 2 | 1% | - | - |
| Prefer not to say  | 26 | 12% | 3 | 43% |
| **Gender identity match gender assigned at birth**  | **No.**  | **%**  | **No.**  | **%**  |
| Yes | 184 | 87% | 4 | 57% |
| No  | 2 | 1% | - | - |
| Prefer not to say  | 25 | 12% | 3 | 43% |
| **Identity** | **No.**  | **%**  | **No.**  | **%**  |
| Woman (including trans woman)  | 166 | 79% | 3 | 43% |
| Man (including trans man)  | 20 | 9% | 1 | 14% |
| Non-binary  | 1 | 0% | - | - |
| Prefer not to say  | 24 | 11% | 3 | 43% |
| **Religion**  | **No.**  | **%**  | **No.**  | **%**  |
| Buddhist  | 1 | 0% | - | - |
| Christian  | 93 | 44% | 2 | 29% |
| Jewish  | 1 | 0% | - | - |
| Muslim  | 1 | 0% | - | - |
| No religion  | 79 | 37% | 2 | 29% |
| Other  | 6 | 3% | - | - |
| Prefer not to say  | 30 | 14% | 3 | 43% |
| **Main language**  | **No.**  | **%**  | **No.**  | **%**  |
| English  | 191 | 91% | 4 | 57% |
| Prefer not to say  | 20 | 9% | 3 | 43% |
| **Physical / mental health conditions or illnesses lasting or expected to last 12 months or more**  | **No.**  | **%**  | **No.**  | **%**  |
| Yes | 54 | 26% | 4 | 57% |
| No  | 135 | 64% | - | - |
| Prefer not to say  | 22 | 10% | 3 | 43% |
| **Condition(s)/illness(es) reduce your ability to carry out day-to-day activities\***  | **No.**  | **%**  | **No.**  | **%**  |
| Yes, a lot  | 9 | 17% | - | - |
| Yes, a little | 28 | 52% | - | - |
| No  | 16 | 30% | - | - |
| Prefer not to say  | 1 | 2% | - | - |
| **Current financial situation**  | **No.**  | **%**  | **No.**  | **%**  |
| I have more than enough money for basic necessities, and a lot spare, that I can save or spend on extras or leisure | 12 | 6% | 2 | 29% |
| I have more than enough money for basic necessities, and a little spare, that I can save or spend on extras or leisure | 98 | 46% | - | - |
| I have just enough money for basic necessities and little else | 51 | 24% | - | - |
| I don't have enough money for basic necessities and sometimes or often run out of money  | 10 | 5% | - | - |
| Not known | 1 | 0% | - | - |
| Prefer not to say  | 39 | 18% | 5 | 71% |

*\*Percentages calculated as a proportion of those who answered that they have a physical / mental health condition.*

# Health Overview and Scrutiny Committees (HOSCs)

The ICB presented information about the public consultation to three health scrutiny committees.

1.5.1 On 3 November 2022 they presented [a written update on the public consultation (Agenda item 6)](https://cmis.essex.gov.uk/essexcmis5/CalendarofMeetings/tabid/73/ctl/ViewMeetingPublic/mid/410/Meeting/4965/Committee/34/Default.aspx) **to Essex Health Overview Policy and Scrutiny Committee**.

The minutes state:

*Committee received the report as written, with a further, verbal update, to be provided at the committee’s February 2023 meeting.*

1.5.2 On 3 November 2022 they [presented information about the public consultation (Item 13)](http://democracy.thurrock.gov.uk/ieListDocuments.aspx?CId=166&MId=6157&Ver=4) to **Thurrock Health and Wellbeing Overview and Scrutiny Committee**.

The minutes state:

*RESOLVED*

*1. The Health and Wellbeing Overview and Scrutiny Committee noted this update and supported the promotion of the consultation.*

*2. Agreed to receive the analysis of public consultation at a future meeting.*

1.5.3 On 29 November the ICB [presented information to **Southend People Committee**](https://democracy.southend.gov.uk/mgCommitteeDetails.aspx?ID=132), under which health scrutiny falls (Item 7).

The minutes state:

*Resolved:*

*1. That the proposals of the Mid and South Essex Integrated Care Board (ICB) for the harmonisation of the provision of the service areas presented to the Committee, be noted.*

*2. That the Committee support the promotion of the consultation on the harmonisation of service delivery by the ICB.*

*3. That the ICB present an analysis of the results of public consultation with regard to the service harmonisation proposals, to a future meeting of the Committee.*

# Miscellaneous responses

In addition to the survey responses and events/focus groups, 27 emails were received about the consultation. Many of these dealt with practical details such as online links not working, queries about being involved in focus groups and information about how the survey link had been passed on or requests to be able to pass it on.

An email was received from the South Essex Director of Social Services, asking whether any discussion had been held with the other two ICSs as equity across the whole of Essex would be the aim. This was responded to with detail about discussions that are in process.

An email was received from an individual who did not have confidence in the process of consultation based on previous experience. The response detailed how NHS Mid and South Essex ICB is committed to considering all comments from residents and stated that discussions are taking place in public.

# Appendices

The Appendices are available as separate documents.

## Appendix 1 – Consultation document

## Appendix 2 – Survey questions

## Appendix 3 – Consultation document – Easy Read

