Appendix 3 – Outcome from consultation

1. Summary

This appendix presents a recap on the process of consultation and an independent analysis of the responses. It highlights the key themes for consideration before reaching a decision about the policy for specialist fertility services.

The sections of this appendix are:

1. **Summary**
2. **Recap on the process**
3. **Who responded**
4. **What people told us**

There are three annexes to this appendix which provide further details for Board members:

Annex A – the original distribution list
Annex B – sample responses from individuals
Annex C – Letters from Infertility Network UK and the National Infertility Awareness Campaign

The key points of this outcome report

We have successfully engaged the target audience
The consultation has reached representatives of the minority group that could be affected by any proposed change in specialist fertility services. The feedback from this group is comprehensive and thought-provoking.

Most respondents were of the view that the CCG should continue with a policy in line with NICE
For those of the opinion that the CCG should continue to fund specialist fertility services under its current policy, the main issues raised were:

- Equality and fairness
- Potential risks to the health and wellbeing of people with fertility problems, if they are unable to access NHS-funded treatment
- Potential costs to the health economy
- Finding other ways to save money

Some respondents were of the view that we should save money by restricting specialist fertility services
For those of the opinion that the CCG should restrict access to specialist fertility services the main issues were:

- Priority spending should be directed towards people who are ill and vulnerable
- Cost-savings should secure “essential” services

Some respondents suggested a different policy change from the options proposed at the start of consultation
During discussions and in written feedback, a frequent view was that the CCG should consider a policy of offering two cycles of IVF. This option was not included in the original consultation document.

We have also highlighted in a “notable issues” section some suggestions for a new approach to a specialist fertility services policy.

Conclusion

The consultation provides a clear view of the implications of infertility for those affected and some wider issues that have not previously been discussed as part of the formal decision-making process.

It is recommended that, in making a policy decision, the CCG Board give full consideration to this outcome and its patient and public perspectives, alongside clinical and financial issues.

2. Recap on the process

Background

The proposed policy change regarding access to specialist fertility services would have a significant impact on some people with fertility problems. The CCG therefore agreed a specific consultation process for this decision, as part of a wider engagement programme on service and financial plans.

The consultation process, which ran from 27 June to 8 September 2014, was designed to open publicly the thinking behind a proposed change in policy and encourage views.

In addition to contacting the established networks of staff, partners, community and patient representatives, the CCG consulted local and national representatives with a specific interest in fertility. This proved effective in reaching the minority group affected within the local population.

Distribution

The consultation document was downloadable from the CCG website and also sent by email to a wide list of contacts, including voluntary organisations with links to hard to reach groups. The original distribution list is included, for information, in annex A.

Publicity and access to the consultation

Details of the consultation, including a list of dates of open meetings, were available from the CCG website, alongside the consultation document and link to an online feedback questionnaire.

People were invited to give their views using any or all of the following channels:

- In writing to the CCG
- In writing using an online feedback questionnaire
- By requesting a meeting with the CCG
- By joining an open workshop session held on
    - 28 July in Maldon
    - 29 July in Witham
    - 30 July in Chelmsford
    - 4 September in South Woodham Ferrers
    - 8 September in Maldon

Many of the organisations and groups on the distribution list subsequently publicised the consultation on their websites and in newsletters.

Press releases gained significant media coverage in all local newspapers, including the list of dates for open meetings. The consultation was featured in the national and trade press, including The Times and Health Service Journal. Balanced reports appeared in news and current affairs programmes on BBC Essex (radio), BBC Look East (TV) and Channel 5's *The Wright Stuff* (TV).

Most of the respondents to the consultation used online access to information and completed the online feedback questionnaire. People with a specific interest in fertility also expressed their views within the open workshop sessions.

The Medical Director, Chief Finance Officer and Director of Nursing and Quality attended a public meeting to hear views from the Essex Health Overview and Scrutiny Committee on 2 July 2014, at the start of the consultation process.

Clinical involvement

GPs and other clinicians are routinely aware of and involved in the application of service restrictions, including those associated with specialist fertility services, as part of providing patient care. The CCG provides information on service restriction policies and updates via clinical newsletters and the CCG website. Proposals for consultation were highlighted using these routine channels and clinicians were invited to have a say as individuals as well as through existing representative channels. A small number of clinicians took up the opportunity to give feedback.

Clinical representative bodies were active in considering the proposals for consultation and the feedback from service users and local people. The main clinical representative groups that discussed the issues were the NICE Guidance sub-group, the Primary Care Forum and the Financial Recovery, Innovation and Transformation (FRIT) Committee. These groups involve representative clinicians from primary care.

It is also relevant that discussions with local GPs concerning CCG commissioning and financial recovery plans started in 2012, as part of the CCG's preparations for authorisation. In November of that year, at a clinical commissioning planning event, a significant number of local GPs suggested that access to specialist fertility services should be further restricted to release savings.

3. Who responded

Written responses

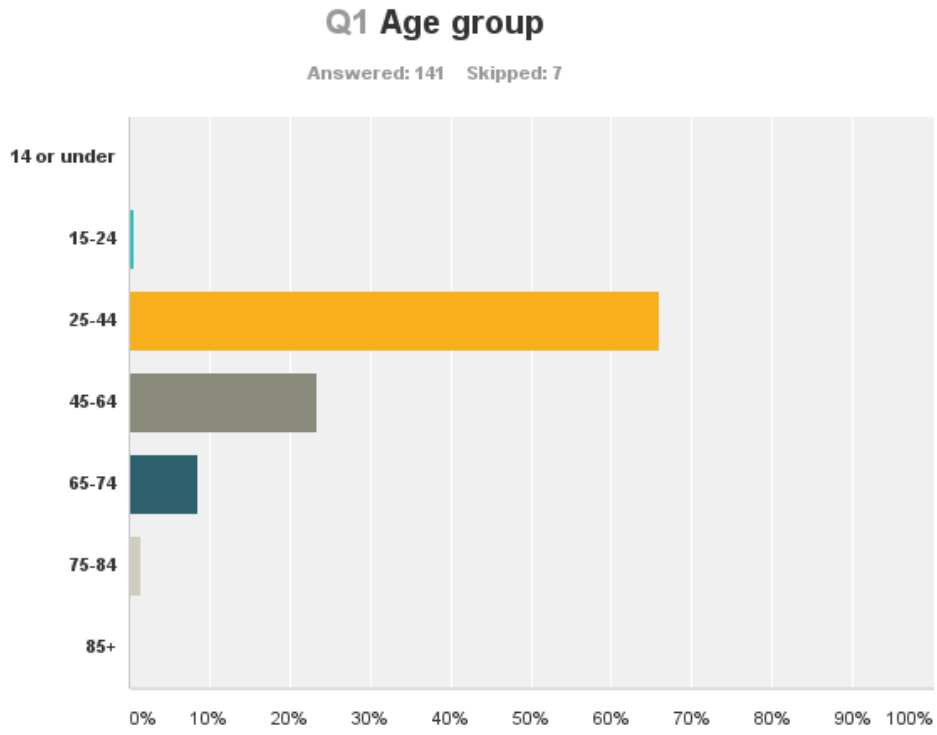
We received written responses from:

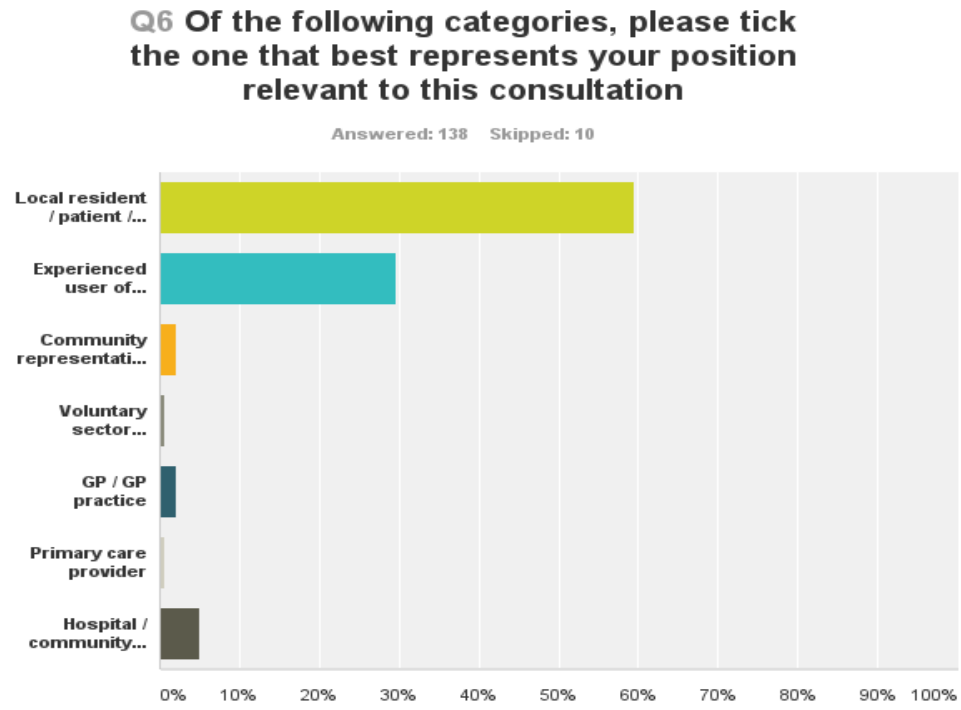
- Over 80 people self-categorised as local resident / patient / carer
- Over 40 people self-categorised as experienced user of fertility services

- Simply Fertility, a private fertility clinic based in Chelmsford
- Baddow Hospital, a private day-case hospital in Chelmsford
- National Infertility Awareness Campaign, an umbrella body, which has the support of a number of organisations working in the field of infertility from professional bodies to patient support groups.
- Infertility Network UK, a charity working to support people with fertility problems in mid Essex and across the UK
- IVFyes, a web-based voluntary group supporting infertility service users

- Fertility nurses at Mid Essex Hospital Services NHS Trust
- Regional Director of Royal College of Nursing
- Four respondents self-categorised as GP / GP practice / primary care provider
- Seven respondents self-categorised as hospital/community services staff

The response to the consultation is most clearly represented by the results of the online feedback questionnaire, which received 148 responses. The majority of these were from the age group 25-44 and self-categorised as local resident / patient / carer, as shown in the two charts below.





Discussions

Those taking part in discussions at the open workshops included:

- Representatives of a range of voluntary organisations including CVSs, Age UK and Arthritis Care
- County, district and parish councillors
- GPs
- Members of Healthwatch Essex
- Members of service user groups and patient participation groups
- Members of the local public

Individual members of Essex Health Overview and Scrutiny Committee (HOSC) were in attendance and gave their views at several of the open meetings, but the HOSC as a body did not express an opinion or preference on the options presented in the consultation.

The Medical Director held a teleconference with several representatives of the National Infertility Awareness Campaign and had a meeting with Infertility Network UK.

Scale of response

The open discussion workshops during this consultation involved over a 100 people, some acting as representatives of wider networks.

Via the online feedback questionnaire, we received 148 responses.

In relation to the number of mid Essex patients that currently access specialist fertility services (some 70 patients per year) , and compared with other similar consultation exercises, the size of response is a good level of representation.

It is important to keep in mind that a consultation process such as this is designed to listen to patient perspectives, specifically those of the group of people most affected. It is not a process to achieve a representative view of a population or electorate.

4. What people told us

Preferred options

We asked people to rank in order of preference the following three proposed options. The consultation document made clear that Option 3 was the CCG's preferred option.

Option 1 – No change to the existing policy
This option means continuing to offer specialist fertility services under the current eligibility criteria set by the CCG's existing policy.

Option 2 – Tighten restrictions from three cycles to one cycle of IVF
This option means continuing to offer specialist fertility services under the criteria set by our existing policy, but would restrict females to receiving one full cycle of IVF (not three as is the current policy).

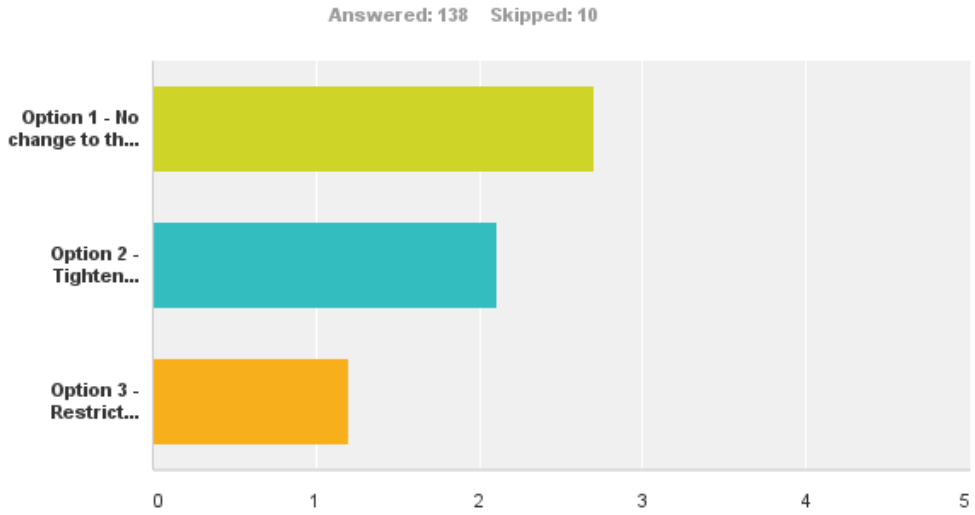
Option 3 – Restrict specialist fertility services to two particular groups of patients
This would limit access to specialist fertility services to:

- Cancer patients who wish to preserve fertility before treatment that is likely to affect their fertility
- Men who are HIV positive and where there is high risk of viral transmission to their female partner.

Results from the online feedback questionnaire

112 respondents ranked Option 1 first
20 respondents ranked Option 2 first
6 respondents ranked Option 3 first
113 respondents ranked Option 2 second

The diagram below represents an average ranking.



Opinions expressed in open discussion workshops

The environment of an open discussion workshop is quite different from giving a private view online. In a group of 10-30 people there are differences of opinion and it was notable in some instances that this created tensions, given the emotional nature of the issue for those participants with a personal interest. For these reasons it is not possible to reach a conclusion about opinions, but simply to take on board the views expressed.

Main themes from feedback

The written feedback and the feedback from discussions followed a similar pattern, which is summarised in the following main themes. These themes are taken from both written and oral comments.

To show how these themes were expressed, we have included some typical responses from individuals in Annex B, including responses from those who would support the proposal to make savings from restricted access to specialist fertility services alongside responses from experienced service users who would prefer the CCG's policy to remain in line with NICE guidance.

Equality and fairness

Most respondents expressed their view that restrictions in access to specialist fertility services and Option 3 in particular, the CCG's preferred option, was unfair for those who needed treatment.

In terms of the nature of the unfairness:

- Potentially it would allow some people, in neighbouring CCGs, for example, to have access to NHS-funded specialist fertility services, whilst the residents of mid Essex would be denied this help.

- The proposed restrictions discriminate against people who cannot afford to pay for treatment.

- Potentially healthy tax-paying people who make few other demands on NHS services would not be able to get NHS support, while other people in the population would have access to NHS-funded solutions for their particular health problems.

- In some responses, people highlighted the issue that infertility may not be the fault of the sufferer, where in other cases of health need, some people may be using NHS resources as a result of poor lifestyle choices, such as smoking, drug and alcohol abuse and obesity. The implication was that this could be a more appropriate area for cost savings.

Prioritisation

People who were supportive of Option 3, or any proposal to make savings in specialist fertility services, did not see these services as “health-related”. They viewed them as low-priority for health spending compared with the health needs of the existing population and those who are vulnerable.

In similar responses, it was viewed that people with illness had a greater need for support.

It was felt by some that savings from specialist fertility services would benefit a wider group of patients.

Potential risks to the health and wellbeing of people with fertility problems

Experienced service users and other respondents frequently emphasised the detrimental affects of infertility. Some people, speaking from experience, described issues including:

- Social stigma and isolation
- Profound emotional and psychological distress
- Suicidal thoughts
- Money problems and debt (for those trying to fund their own treatment)
- Breakdown of family relationships and functions
- Impact on physical health

Associated with this feedback is the assertion that it is difficult for those who have not experienced infertility to understand the implications. Acknowledging this, we have attached at annex B five sample responses from experienced service users.

Potential costs to the health economy as a consequence of a change in policy

Some feedback suggested that unforeseen costs could arise in association with the potential health and wellbeing risks described above, such as in mental health and primary care, for example.

A small number of respondents, including Infertility Network UK, suggested that patients seeking treatment in the private sector could choose cheaper overseas clinics, which could lead to an increase in multiple births and a consequent demand on local NHS neonatal intensive care services. The cost of just one birth of triplets, for example, could reduce any cost savings from restricted access to specialist fertility services.

Savings to maintain "essential" services

Some respondents accepted the proposition that financial pressures for mid Essex had reached a stage where services that considered "essential" could be at risk unless savings could be released.

During discussions at the open workshop sessions, we were able to pursue this view and question what people thought were "essential" services. Cancer treatment was quoted as the main example.

Other themes

Other issues raised in both written and oral feedback included:

- Concerns about whether the CCG's preferred option for a proposed policy change met with the guiding principles of the NHS and/or basic human rights.

- Concerns about the CCG taking a backward step from being one of the first to apply NICE recommendations to one of few CCGs only to offer specialist fertility services and IVF in certain very limited cases.

- Concerns about patients being encouraged to use private care (expressed as "privatisation of the NHS via the back door")

- Specialist fertility services should be offered only to childless couples.

- Infertility is a recognised medical condition with treatment guidelines set by the National Institute for Health and Care Excellence (NICE)

- The needs of young people with potentially good health outcomes should have a higher priority for health spending than the needs of an older population and those with poor health due to lifestyle choices.

- A number of respondents did not view that HIV and cancer patients were any more deserving than healthy patients. Some went as far as to question whether people with such health risks should be contemplating having a baby.

The written submissions from Infertility Network UK and the National Infertility Awareness Campaign are well-articulated cases that cover most of the themes raised during the consultation process. We have included these submissions in full in annex C.

Notable issues for consideration

In addition to giving views on the proposed options for a change in policy, we encouraged people, to discuss all things relevant to local needs and service planning for specialist fertility services. The responses summarised in this section raise issues that were not in the original proposals of the consultation document.

Several people or just one individual respondent may have raised some of the following points. Without weighting these points in any way, they are worthy of note and consideration in finding a solution to the need for savings.

Ideas for an alternative approach to securing savings

- Part payments for treatment, or a subsidised approach.

- Amend the policy to allow two cycles of IVF. For people who need treatment, this would be better than having no access at all, and would potentially offer savings. Respondents advocating two IVF cycles, suggested that this would be better value for money in terms of health outcomes, as it would have a greater rate of success than one cycle. Experienced service users talked about how problems may be uncovered in the first cycle that can then be addressed in a second.

- Set the policy at one cycle, but with a protocol that would allow a second cycle if the clinical evidence showed high chances of success.

- Offer IUI (no further evidence given)

- Increase egg sharing and sperm sharing (no further explanation given)

- Find savings from other healthcare areas e.g. by restricting treatments for self-inflicted health problems, such as those caused by smoking, substance abuse and obesity.

- Find savings by reducing management costs.

Suggestions for a new policy approach

A small number of respondents, mainly professionals who work in fertility services, put forward the idea that a more discerning policy could deliver savings and improve health outcomes for people with infertility problems.

The suggestion was that we could make better use of clinical procedures to assess the likelihood of conception success for an individual or couple, and treat only those most likely to be successful. Such a policy would be based upon a more tailored, individual approach that would avoid spending on ineffective treatment.

The argument in favour of this approach was that it could potentially secure savings that are comparable with a blanket restriction and its potential

consequences of multiple births. The main difference would be that a more flexible policy would gain better health outcomes for people with fertility problems.

Suggestions for policy implementation

- There should be a well thought through lead-in process to put a new policy into effect. GPs and service providers would need to make adjustments. A plan could be agreed in partnership with service providers.

- Patients already in the system should be allowed to continue with treatment.

- Professionals and patients need straightforward, easy to navigate procedures, avoiding unrealistic expectations of doctors and nurses.

- A new policy would require a good communication strategy for patients, providers and the general public. This should include making clear the next policy review date.

Ideas for support to people with fertility problems

- Develop a substantial support plan in partnership with social services and mental health services, including offering counseling and an adoption information course. This should be in operation before taking steps towards specialist fertility services, and people should be given time to think.

- Patients who are planning to self-fund should receive NHS-funded support and guidance.

- Fertility patients should have access to good advice and information e.g. about voluntary and support organisations and private sector services.

- People should be treated with expertise, respect and kindness.

Annex A – original distribution list

BME minority liaison contacts in mid Essex
British Fertility Society
British Infertility Counselling Association
Care Fertility
Children's Centres in Mid Essex
District, Town and Parish Councils in mid Essex
Essex CCGs and CSU
Essex County Council (including Adult Social Care Services and Children and Young People's Care Services)
External support organisations involved in mid Essex health economy
Fertility UK
GP practices in mid Essex
Health and Wellbeing Board
Health Overview and Scrutiny Committee
Healthwatch
Hospitals and service providers in Essex
Infertility Network UK
Local MPs
Mid Essex contacts for groups representing people with disabilities
Mid Essex Patient Reference Groups
Mid Essex Primary Care Forum
Mid Essex System Leadership Group
National Childbirth Trust covering mid Essex
National Infertility Awareness Campaign
NHS England (Essex and Midlands and East)
Patient participation groups (Trusts and GP practices)
Press and media contacts
Specialist Fertility Services providers
Voluntary sector organisations in mid Essex

Annex B – Sample responses from individuals

Response 25

PAGE 1: Some basic information about you

Q1: **Age group**

- 65-74

Q2: **Sex**

- Female

Q3: **Ethnicity**

- White

Q4: **Do you have a registered disability?**

- No

Q5: **Where in mid Essex do you live, or represent?**

- Chelmsford City

Q6: **Of the following categories, please tick the one that best represents your position relevant to this consultation**

- Community representative (e.g. councillor, patient group member)

Q7: **If you are responding on behalf of a group or organisation, please give the name of your group or organisation**

Respondent skipped this question

PAGE 2: Your views on a proposed policy change for specialist fertility services

Q8: **Having read the consultation document and considered the pros and cons of the proposed changes in policy, please indicate your preferences by numbering the following options 1 to 3, where number 1 is your first preference. Please note: The order of the options below will change once you have made your first selection, to reflect your preference. You will need to make a second choice and the remaining will automatically appear. Please check your order before you submit the survey.**

1. **Option 2 - Tighten restrictions from three cycles to one cycle of IVF (savings up to £250,000)**
2. **Option 3 - Restrict specialist fertility services to two particular groups of patients (savings up to £550,000)**
3. **Option 1 - No change to the existing policy (no financial savings)**

Q9: **Please check the options are now displayed in the order you have chosen**

- I confirm the options above are now arranged in my order of preference

PAGE 3

Q10: **If you would like to suggest a different policy change, please explain below:**

Didn't really want to choose either option 2 or 3 at all I don't like positively discriminating cancer and HIV groups as they may not be the best people to parent children when they may not be alive or fit enough to carry out their parental responsibilities.

Q11: **Given the reasons for a proposed change in policy, how do you feel that your preferred option is in the best interests of local people?**

Need to save money

Q12: **What particular things do you think the CCG should consider when making its policy decision about specialist fertility services?**

- **In relation to people with fertility problems**

Infertile women are not ill and the NHS is cash strapped. Too many people on this earth. Let's prioritise looking after the ill and disabled first

- **In relation to the mid Essex population as a whole**

As above

Q13: **What particular things do you think should be considered when putting policy into practice?**

Means testing Other cash strapped services eg care of the elderly with dementia

Q14: **Any other comments?**

We shouldn't provide services we can't afford

Response 32

PAGE 1: Some basic information about you

Q1: Age group

- 45-64

Q2: Sex

- Female

Q3: Ethnicity

- White

Q4: Do you have a registered disability?

- No

Q5: Where in mid Essex do you live, or represent?

- Maldon District

Q6: Of the following categories, please tick the one that best represents your position relevant to this consultation

- Local resident / patient / carer

Q7: If you are responding on behalf of a group or organisation, please give the name of your group or organisation

Respondent skipped this question

PAGE 2: Your views on a proposed policy change for specialist fertility services

Q8: Having read the consultation document and considered the pros and cons of the proposed changes in policy, please indicate your preferences by numbering the following options 1 to 3, where number 1 is your first preference. Please note: The order of the options below will change once you have made your first selection, to reflect your preference. You will need to make a second choice and the remaining will automatically appear. Please check your order before you submit the survey.

Order of Preference

1. **Option 2 - Tighten restrictions from three cycles to one cycle of IVF (savings up to £250,000)**
2. **Option 3 - Restrict specialist fertility services to two particular groups of patients (savings up to £550,000)**
3. **Option 1 - No change to the existing policy (no financial savings)**

Q9: Please check the options are now displayed in the order you have chosen

- I confirm the options above are now arranged in my order of preference

PAGE 3

Q10: If you would like to suggest a different policy change, please explain below:

Respondent skipped this question

Q11: Given the reasons for a proposed change in policy, how do you feel that your preferred option is in the best interests of local people?

Respondent skipped this question

Q12: What particular things do you think the CCG should consider when making its policy decision about specialist fertility services?

- **In relation to people with fertility problems**

acknowleging the trauma and healthy effects (in particular mental well being) of infertlity

- **In relation to the mid Essex population as a whole**

Recognising the need to balance costs of and prioritisation of treatment for those suffering illness or disease

Q13: What particular things do you think should be considered when putting policy into practice?

Respondent skipped this question

Q14: Any other comments?

Having been affected by infertility, and undergoing unsuccessful IVF I know the distress and trauma that infertility can cause, and the ray of hope that this treatment can bring. Unfortunately the success rates are really low, and the cost very high, and consequently, even though I believe IVF should be funded, it should not be at the expense of clinical treatment for those will illness and disease. I believe option 2 is a reasonable compromise which delivers some savings, whilst offering some small hope to those affected by fertility issues.

Response 51

PAGE 1: Some basic information about you

Q1: Age group

- 25-44

Q2: Sex

- Female

Q3: Ethnicity

- White

Q4: Do you have a registered disability?

- No

Q5: Where in mid Essex do you live, or represent?

- Chelmsford City

Q6: Of the following categories, please tick the one that best represents your position relevant to this consultation

- Experienced user of fertility services

Q7: If you are responding on behalf of a group or organisation, please give the name of your group or organisation

Respondent skipped this question

PAGE 2: Your views on a proposed policy change for specialist fertility services

Q8: Having read the consultation document and considered the pros and cons of the proposed changes in policy, please indicate your preferences by numbering the following options 1 to 3, where number 1 is your first preference. Please note: The order of the options below will change once you have made your first selection, to reflect your preference. You will need to make a second choice and the remaining will automatically appear. Please check your order before you submit the survey.

Order of Preference

- **Option 1 - No change to the existing policy (no financial savings)**
- **Option 2 - Tighten restrictions from three cycles to one cycle of IVF (savings up to £250,000)**
- **Option 3 - Restrict specialist fertility services to two particular groups of patients (savings up to £550,000)**

Q9: Please check the options are now displayed in the order you have chosen

- I confirm the options above are now arranged in my order of preference

PAGE 3

Q10: If you would like to suggest a different policy change, please explain below:

Additional support needs to be put in place for couples who are experiencing problems with fertility. Having been through a horrible experience myself, I would have benefited from appropriate counselling support. However this is not in place. If it were, couples might pursue alternative options and other consequences that cost the CCG money, such as mental health issues, could be cut. I believe that these proposals have not included all possible efficiencies.

Q11: Given the reasons for a proposed change in policy, how do you feel that your preferred option is in the best interests of local people?

Equality of access to fertility options. Clearly more important to have emergency health care than fertility support. However, unresolved fertility issues impact significantly on individuals' (mental & physical) health. What is the evidence that the proposed changes are anything but short-termist and reactionary?

Q12: What particular things do you think the CCG should consider when making its policy decision about specialist fertility services?

- **In relation to people with fertility problems**

mental health & wellbeing issues

Q13: What particular things do you think should be considered when putting policy into practice?

Long term health issues - not just what the current government/chief exec needs to do. I understand that the first cycle of IVF is rarely successful. I would like to see evidence that this scenario is good value for money.

Q14: Any other comments?

My personal experience of the process what that it was inefficient, poorly marked out and non-individual. After years of fertility issues, what I really needed was to talk to someone who could help me make an informed and rational decision. I am lucky that I had other support - what would the costs to the CCG have been if I hadn't?

Response 92

AGE 1: Some basic information about you

Q1: Age group

- 25-44

Q2: Sex

- Female

Q3: Ethnicity

- White

Q4: Do you have a registered disability?

- No

Q5: Where in mid Essex do you live, or represent?

- Braintree District

Q6: Of the following categories, please tick the one that best represents your position relevant to this consultation

- Local resident / patient / carer

Q7: If you are responding on behalf of a group or organisation, please give the name of your group or organisation

Respondent skipped this question

PAGE 2: Your views on a proposed policy change for specialist fertility services

Q8: Having read the consultation document and considered the pros and cons of the proposed changes in policy, please indicate your preferences by numbering the following options 1 to 3, where number 1 is your first preference. Please note: The order of the options below will change once you have made your first selection, to reflect your preference. You will need to make a second choice and the remaining will automatically appear. Please check your order before you submit the survey.

Order of Preference

1. **Option 1 - No change to the existing policy (no financial savings)**
2. **Option 2 - Tighten restrictions from three cycles to one cycle of IVF (savings up to £250,000)**
3. **Option 3 - Restrict specialist fertility services to two particular groups of patients (savings up to £550,000)**

Q9: Please check the options are now displayed in the order you have chosen

- I confirm the options above are now arranged in my order of preference

PAGE 3

Q10: If you would like to suggest a different policy change, please explain below:

Respondent skipped this question

Q11: Given the reasons for a proposed change in policy, how do you feel that your preferred option is in the best interests of local people?

I am currently going through the NHS with fertility issues. This has been ongoing for 2 years. If the policy was to change just as we are about to be eligible for referral I would feel let down by the system. We have been honest about our situation, done all that has been asked of us. Had all the tests offered and taken medication prescribed. We are now ready to move forward with IVF but need to wait for a referral at the end of September. The last two years will have been for nothing if the policy changes. In that time we could have been saving for our own treatment. Now we feel like we are being penalised because we do not have cancer or HIV if this is the policy change. What makes people with cancer of HIV needs more than someone who has no other conditions. Those that suffer with fertility issues go through such a hard time struggling with something that comes naturally to most. It would be unfair to discriminate against those that are healthy. Their needs for a family are just as great as someone with cancer or HIV. We offer many other treatments on the NHS that are self inflicted illness such as smoking related illnesses and people with body image disorders and yet those seeking a family of their own are being punished when they cannot control their fertility issues. I feel that Mid Essex CCG should stay with the NICE recommended guidelines. As a working adult who has been in continuous employment for 19 years paying taxes I would be very disappointed that when I am in need of the NHS services I am denied.

Q12: What particular things do you think the CCG should consider when making its policy decision about specialist fertility services?

- **In relation to people with fertility problems**

Peoples mental health with all the stress that fertility issues bring.

- **In relation to the mid Essex population as a whole**

Mid Essex poplulation currently benefit from the NICE
guidelines. To have this taken away would be detrimental to the area.

Q13: What particular things do you think should be considered when putting policy into practice?

Respondent skipped this question

Q14: Any other comments?

Respondent skipped this question

Response 140

PAGE 1: Some basic information about you

Q1: Age group

- 25-44

Q2: Sex

- Female

Q3: Ethnicity

- White

Q4: Do you have a registered disability?

- No

Q5: Where in mid Essex do you live, or represent?

- **Outside of mid Essex, please state where**

Colchester

Q6: Of the following categories, please tick the one that best represents your position relevant to this consultation

- Experienced user of fertility services

Q7: If you are responding on behalf of a group or organisation, please give the name of your group or organisation

Respondent skipped this question

PAGE 2: Your views on a proposed policy change for specialist fertility services

Q8: Having read the consultation document and considered the pros and cons of the proposed changes in policy, please indicate your preferences by numbering the following options 1 to 3, where number 1 is your first preference. Please note: The order of the options below will change once you have made your first selection, to reflect your preference. You will need to make a second choice and the remaining will automatically appear. Please check your order before you submit the survey.

Order of Preference

1. **Option 1 - No change to the existing policy (no financial savings)**
2. **Option 2 - Tighten restrictions from three cycles to one cycle of IVF (savings up to £250,000)**
3. **Option 3 - Restrict specialist fertility services to two particular groups of patients (savings up to £550,000)**

Q9: Please check the options are now displayed in the order you have chosen

- I confirm the options above are now arranged in my order of preference

PAGE 3

Q10: If you would like to suggest a different policy change, please explain below:

See other comments

Q11: Given the reasons for a proposed change in policy, how do you feel that your preferred option is in the best interests of local people?

See other comments

Q12: What particular things do you think the CCG should consider when making its policy decision about specialist fertility services?

- **In relation to people with fertility problems**

See other comments

Q13: What particular things do you think should be considered when putting policy into practice?

See below

Q14: Any other comments?

Addendum to consultation response. At the age of 31 I decided with my husband to start a family. This decision was not made lightly; it followed a decision to commit to a family life by marriage, forging good careers and establishing financial security. Both my husband come from close, loving supportive families and felt as though we were in a positon to offer a child a wonderful life where they could flourish. Sadly we discovered that this would not be possible without fertility treatment due to my bodies own failings. My world crashed around me, I felt had failed as a wife and as a woman. Surely as a woman it is my right to have a child? Especially a woman who had done all she could to ensure the best possible life for a child that came along? Evidently not? It was when we started on this journey that we discovered so many others of our age, of our own and other professional

standings, who had worked hard to provide a child a good life, could also not conceive naturally. You ask about the silence in response. This is because unless you are within the medical profession, unless you have faced the trauma of infertility personally or from those around you, it is not something that touches you. Having a baby is such everyday news. At that time it also became abundantly clear that the provision of services differed so vastly around the country, a “postcode lottery”. How was that fair we asked as we watched our close friends face failure after one cycle and the distress of having to somehow raise funds to start private treatment. We saw their parent’s cash in pension funds to help their children have their own. We have seen friends re-mortgage. What simply is not recognised is the impact psychologically and sociologically when you are faced with infertility. I became someone I was not. I regressed; I was torn apart with guilt and failure. It was not something we spoke of outside the family circle; it was not something I could ever speak freely of until now 3 years on. Then there is the medical treatment. The medical professionals are wonderful, kind caring and attentive. The procedures themselves painful, at times degrading and heart breaking. It takes time to recover physically and mentally. The withdrawal of funding for treatment takes away from those so committed to raising a child that possibility. It can cause psychological ramifications for the rest of their life and financial hardship. It can end marriages, friendships and family relations. The potential cost to the NHS in funding long term mental health support, the cost to society of not giving those potential children a right to a promising life and the impact on the social demographic.

Annex C – Letters from Infertility Network UK and NIAC

21st August 2014

Dear Sirs

Response from Infertility Network UK to the mid-Essex consultation

We are a charity working to support those with fertility problems Mid-Essex and across the UK. Infertility is a recognised medical condition, and the 2013 NICE guidance recommends the provision of three full cycles of IVF for eligible couples. This is the appropriate treatment for a medical condition - and the commissioning of fertility services is a clinical decision. The NICE guidance should be used, and this has been reinforced by the May 2014 draft Quality Standard.

NICE guidance is based on clinical effectiveness and cost effectiveness and the evidence is put together after much research and consideration. The CCG has proposed to cut services due to financial considerations, and has chosen to ignore the evidence from NICE. The CCG has decided that fertility should not be a priority, but no evidence is given as to why fertility services should be delegated to a lower priority than other treatments.

In our opinion, Option 1 is the only acceptable option as it is the nearest to fulfilling the guidance from NICE which represents good clinical practice. It is, however, still not meeting the guidance from NICE which would also mean offering one full cycle of treatment to a limited group of women aged 40-42.

Option 2 would be totally inadequate. It would not only restrict provision, but would also put those who yield fewer viable embryos at an immediate disadvantage. NICE does not recommend one cycle as this is neither clinically nor cost effective.

Option 3 is completely unacceptable. It is not based on any kind of evidence. It is not clear why these two groups have been singled out. Neither group is constituted of fertility patients, and yet they would be the only people to receive fertility treatment.

Marking out HIV positive men and offering them IUI with washed sperm is a particularly odd decision when NICE is very clear that sperm washing does not eliminate the risk of HIV transmission (NICE 1.3.10.5). NICE guidance says that where men are HAART compliant, have a plasma viral load of less than 5O copies/ml for more than six months and where there are no other infections present; the risk of transmission to the female partner through unprotected sexual intercourse is negligible.

Option 3 would mark a drastic departure from the NICE guidelines, and would be wholly inadequate as far as patient and national policy maker expectations are concerned.

The main consideration of any CCG in commissioning decisions should be the advice of NICE, contained in their Quality Standards and Guidelines. The fertility guideline is very clear that three full cycles are to be provided and this is based on both cost and clinical effectiveness. NICE is the body best placed to make this judgement.

It is also important to remember that not everyone would receive three cycles automatically. Only a small percentage of patients actually need this third cycle, and the responsible clinician can still use their discretion if they feel it would not be in the patient's best interests to progress with a further cycle of treatment. Nevertheless, the option needs to be at the very least made available to clinicians and patients.

The restriction of fertility services raises serious questions of equality since other CCGs may continue to offer wider access to specialist fertility services. Should Mid-Essex choose to approve Option 3, this would make the area the worst in the country as far as the provision of NHS funded fertility treatment is concerned. It would exacerbate the widening of a post-code lottery in a region that, up until fairly recently, was considered the best in the country.

Infertility Network UK is further concerned that these proposals could lead to an increase in multiple births in mid-Essex as patients seek treatment in the private sector and often overseas. We know that cheaper overseas clinics are attractive to patients who do not receive NHS funding, and the 2006 One Child at a time HFEA expert advisory group report makes it clear that inadequate NHS funding is an obstacle to reducing multiple births. The cost of a single premature triplet birth involving neonatal intensive care for the babies could soon wipe out any savings made from the proposed reduction in IVF services. This is not a risk that anyone should be prepared to take - and we would like to know how the CCG plans to address this as multiple birth is the biggest health risk from IVF treatment.

The emotional impact of these proposals should not be underestimated. Infertility is a devastating medical condition - and these proposals will condemn many mid-Essex patients to a lifetime of involuntary childlessness.

Yours faithfully

Susan Seenan
Chief Executive

Submission to Mid Essex CCG consultation on IVF services (July 2014)

NIAC and its aims are supported by the following organisations:

Fighting for funding

THE NATIONAL INFERTILITY AWARENESS CAMPAIGN (NIAC)

NATIONAL INFERTILITY AWARENESS CAMPAIGN

Consultation Submission

Having read the consultation document and considered the pros and cons of the proposed changes in policy, please indicate your preferences by numbering the following options 1 to 3, where number 1 is your first preference.

Option 1 – No change to the existing policy (No financial savings)	1
Option 2 – Tighten restrictions from thee cycles to one cycle of IVF (Savings up to £250,000)	2
Option 3 – Restrict specialist fertility services to two particular groups of patients (Savings up to £550,000)	3

Given the reasons for a proposed change in policy, how do you feel that your preferred option is in the best interests of local people?

The Mid Essex CCG has based proposed fertility cuts on the basis of financial considerations. However ultimately the commissioning of specialist fertility services is a clinical decision, to be made with reference to the available recommendations, guidelines, and quality standards of NICE. The 2004 and 2013 iterations of the NICE guideline on fertility recommend the provision of three full cycles of IVF to eligible couples. This is additionally reinforced by the draft Quality Standard, published in May 2014.

The consultation document issued by Mid Essex CCG stated that there '*was a general agreement among CCG member practices that other types of healthcare should take priority over fertility services*'. NIAC disputes this assessment of specialist fertility services as a low priority, and questions why specialist fertility services have been given this designation compared to other treatments.

Infertility is a recognised medical condition, and evidence suggests it can have a devastating emotional impact . It can cause distress, depression and relationship breakdown. This psychological impact has been recognised by NICE in their Clinical Guidelines, which recommend that couples '*should be offered counselling because fertility problems themselves, and the investigation and treatment of fertility problems, can cause psychological stress*'.

Option 1 in the consultation document is the preferable option because it is the closest to best practice as set out in the NICE clinical guidelines.

Option 2 would be inadequate because not only would it restrict provision but it would also place couples that yield fewer viable embryos at an immediate disadvantage. Some couples may only yield one viable embryo for transfer in each cycle. This is just one reason why it is essential that up to three cycles of treatment be provided. Each '*full*' cycle should include the subsequent transfer of any stored, frozen embryos, in accordance with the NICE guideline.

Option 3 would leave the population of Mid Essex, excepting two very small groups, with no access to fertility services. As the CCG have themselves noted this would mark a drastic departure from the NICE guidelines, and would be wholly inadequate as far as patient and national policymaker expectations are concerned.

What particular things do you think the CCG should consider when making its policy decision about specialist fertility services

In relation to people with fertility problems:

The main consideration of any CCG in commissioning decisions should be the advice of NICE, contained in their Quality Standards and Guidelines. NICE balances clinical effectiveness and cost effectiveness, and as such their guidance is intended to optimise the outcome for the patient. With their expertise they are the body best placed to make such assessments.

In the fertility guidelines NICE has been unusually prescriptive in their recommendation on the number of cycles to be provided, and there are good evidence-based reasons for this. Three has been demonstrated to be the optimal number of cycles for maximising the chances of a successful pregnancy.

It is also important to remember that not everyone would receive three cycles. Only a small percentage of patients will actually need this third cycle, and the responsible clinician can still use their discretion if they feel it would not be in the patient's best interests to progress with a further cycle of treatment. Nevertheless, the option needs to be at the very least made available to clinicians and patients.

In relation to the Mid Essex population as a whole:

Infertility is not a statistically insignificant problem, NICE estimates that it affects 1 in 7 heterosexual couples in the UK. This represents a significant segment of the Mid Essex population.

Furthermore, as the Mid Essex consultation notes, the restriction of fertility services raises serious questions of equality since other CCGs may continue to offer wider access to specialist fertility services. Indeed NIAC has recently received confirmation that all other CCGs in the UK will now commission at least one cycle of IVF. As such were Mid Essex to approve option 3 of the consultation document the CCG would effectively relegate itself to the worst position in the country as far as the provision of NHS funded fertility treatment is

concerned. This would also exacerbate the widening of a postcode lottery in a region that, up until fairly recently, was considered the best in the country.

What particular things do you think should be considered when putting policy into practice?

Whichever option Mid Essex ultimately decides upon stakeholders – including GPs, consultants and patients - should be quickly alerted to the details of the new policy.

Patients currently undergoing treatment should also be informed that their eligibility would not be affected. Additionally Mid Essex should set a review date for their specialist fertility policy and alert the aforementioned stakeholders well before such a review takes place.

A report conducted by NIAC in January 2014 found that the majority of CCGs do not publish their commissioning policies on their website. As such NIAC has written to several CCGs regarding their lack of transparency. We would hope that Mid Essex would clearly publish and label their policy online, and suggest that it should not be hidden amongst CCG board papers or grouped in with several other perceived '*low priority*' treatments.

Any other comments?

The Mid Essex consultation notes that '*Very few CCGs offer three full cycles. Some offer two cycles, some offer one cycle and some CCGs do not offer IVF treatment*.' NIAC strongly believes that clinical decisions should not be based upon the under performance of other CCGs. Whilst Mid Essex should consider any disadvantages imposed upon its patients, the CCG should not cut provision that is meeting clinical guidelines merely because other CCGs are themselves failing in this responsibility. It should also be stated that 25% of CCGs offer 3 cycles at present, we do not feel that this constitutes '*very few*'. In addition, NHS England has recently committed to providing three full cycles of IVF for armed forces personnel.

NIAC feels it is worth noting that should the CCG decide to proceed with Option 1, then Mid Essex will need to robustly justify their failure to meet guidelines on the provision of a cycle for women between 40 and 42. Especially considering the recent Thanet CCG court case, where it was decided that a CCG must provide clear reasons for any clinical commissioning policy that does not follow NICE guidance.

About NIAC

The National Infertility Awareness Campaign (NIAC) is an umbrella body, which has the support of a number of organisations working in the field of infertility from professional bodies to patient support groups.

For more than 20 years NIAC has campaigned for people to have comprehensive and equal access to a full range of appropriate NHS investigations and treatments for infertility; this includes the right to access up to three cycles of IVF treatment free on the NHS.

NIAC is shortly to be re-launched as Fertility Fairness (see http://www.fertilityfairness.co.uk/)

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