

Appendix 2

Specialist Fertility Consultation

Key Findings from the Formal Consultation

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November 2014

NHS – Add Protective Marking Category Here



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Background

Until March 2013, specialist fertility services were commissioned regionally by the East of England Specialised Commissioning Group (EoE SCG). Since April 2013, individual Clinical Commissioning Groups became responsible for commissioning these services.

Bedfordshire Clinical Commissioning Group (BCCG) has been working with Clinical Commissioning Groups (CCGs) in the East of England to procure region wide specialist fertility service via a collaborative agreement (made up of 19 CCGs within the EoE region).

The East of England wide collaborative addresses the contractual element of the service i.e. the service providers, while each individual CCG determines their own eligibility criteria and policy that will specify service user access to the service.

Coupled with this change, the National Institute for Health and Clinical Excellence (NICE)¹ updated their guidance in respect of fertility in February 2013. (CG156, February 2013). The updated policy recommended that access to IVF was reduced from 3 years to 2 years and that women aged between 40-42 years should be offered one cycle.

Current BCCG Policy

The current policy which BCCG follows includes the following criteria:

- Access to IVF after 3 years of unexplained infertility
- Aged between 23-40 years
- 3 full cycles of IVF

Financial Implications for BCCG

BCCG currently spends £799,000 each year on specialist fertility treatments. If BCCG commissions future specialist fertility services in line with all recommendations in the revised NICE guidance, it would need to find an additional £289,000 – an increase of 36% of the current IVF budget. In a climate where additional funding is absent, the reality of implementing the NICE recommendations in their entirety would result in the requirement to decommission health services elsewhere in Bedfordshire.

¹ NICE provides various types of national guidance on promoting good health and preventing and treating ill health. The fertility guidance referred to within this report is one that provides recommendations about the treatment and care of fertility. This type of guidance is not mandatory for commissioners to follow and fund its recommendations. This type of guidance is very different from the 'technology appraisal guidance' produced by NICE which is mandatory for CCGs to fund.

Clinicians from the East of England collaborative worked to identify a number of alternative potential commissioning options that comprised a variation of elements of the revised NICE guidance along with variations that diverge from the NICE guidelines.

These discussions further resulted in the identification of a future commissioning option that clinicians in the EoE considered to be the best value for money option if CCGs were unable to fund the revised NICE guidelines in full. The option includes the following:

	Waiting time for access to IVF	Age restrictions	Number of cycles
Option 1 EoE collaborative recommended option	Access to IVF after 3 years	Aged 23 to 42 years	2 full cycles of IVF treatment for women age 23 to 40 1 full cycle of IVF treatment for women aged 40-42

Clinicians considered the EoE recommended option as the option that is closest to the revised NICE guidelines with the least financial implication. Extending the age range in line with the NICE guidelines enables women aged 40 to 42 to access IVF whilst they previously were excluded. Therefore this option provides opportunity for more of the population to access IVF than the other options and the existing criteria.

Locally, Bedfordshire CCGs executive management team acknowledged that additional funding for the application of the revised NICE guidance in full is not available. They therefore considered that the consensus recommendation by the clinicians from the EoE collaborative (Option 1) would also be Bedfordshire CCG's preferred option, given that it increases the availability of IVF to patients whilst remaining in budget and thereby not risking decommissioning of other services. However, the executive management team also recognised the sensitivities of any decisions in this area and the need for consultation with the public before making a final recommendation to the CCG governing body.

The Full Case for Change can be found in Appendix A

Report Summary

Consultation Institute – Quality Assurance

From the start of this project, BCCG understood the complexities and emotiveness of the subject matter, but also recognised the small number of Bedfordshire residents that it affected. They also felt that this would be an ideal opportunity to develop a blueprint for smaller consultations that could be used in the future. For that reason, BCCG asked the Consultation Institute to quality assure the consultation process. The Consultation Institute is a nationally recognised body of experts in formal consultation who advise and assure the development of engagement and consultation plans.

Stakeholder Mapping

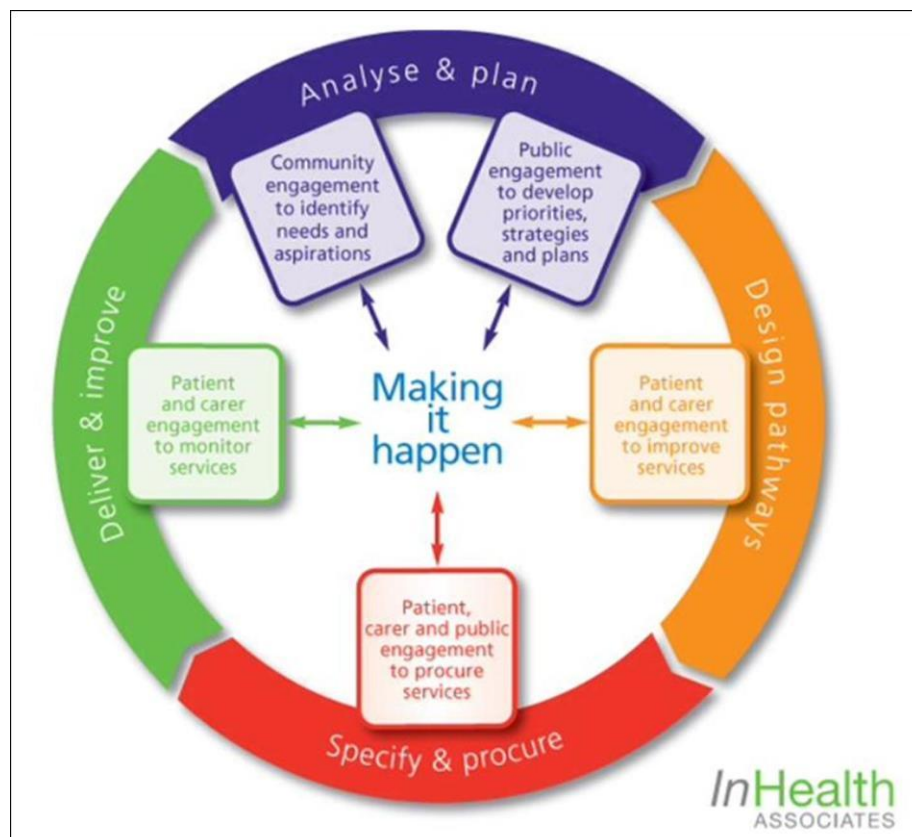
To establish who the key stakeholders were in this process, the project manager and the patient and public engagement manager, spent some time going through a stakeholder mapping exercise. This ensured that BCCG identified the stakeholders needed to involve in the engagement and consultation moving forward. BCCG also challenged themselves to try to engage potential patients of the future- i.e: those members of the public who might need specialist fertility services in the future, but didn't know it yet. This meant that BCCG needed to target general members of the public as well as past and present service users.

The stakeholder map can be found in Appendix B.

Summary of Activity

BCCG wanted to ensure that members of the public, patients and those who had an interest in specialist fertility had the opportunity to be involved in the project from the very beginning. It was also felt that they would be a good sounding board to ensure that BCCG would produce a consultation that would take personal views and experiences sufficiently into account. For this reason, at the start of the project BCCG decided to recruit a stakeholder forum to work with the project manager and engagement manager to complete the pre-consultation engagement phase.

This fits in with BCCG's Communication and Engagement Strategy which embraces the engagement cycle first seen in the 'Transforming Participation in Health and Care Paper, published by NHS England in November 2013.



Stakeholder forum

BCCG went out to their public membership, the GP Patient Participation Groups and the locality patient network groups to ask for volunteers to join our stakeholder group. BCCG successfully recruited eight members of the public, which included retired nurses, a psychologist specialising in fertility issues, two members of the public engagement forum, a Healthwatch representative and a local GP.

They met on three occasions throughout the project and were integral to the process that followed. BCCG were initially cautious about how much influence the stakeholder group would be able to have, with much of the scope having already been undertaken by the EofE and a preferred option already on the table and a lot of the criteria (such as BMI, smoking, children from previous relationships etc) not under review. However, once they came together, it soon became apparent just how much the stakeholder group could influence – from option development, to consultation document content, to places BCCG should send the forms, through to locations BCCG could visit to speak to the members of the public.

The initial meeting held on 15 July 2014 initiated discussions around specialist fertility services and the budget involved, as well as the history of the service. The group touched on the issues surrounding specialist fertility services, and in particular IVF, for couples who are struggling to conceive. The group also spent some time talking about potential options for the future, how that worked with the budget available to BCCG and how the consultation document would need to be written with empathy yet honesty surrounding the financial implications BCCG face. Indeed, they looked at the options offered by the EofE collaborative, and then worked with the project manager to exclude one of those options and come up with a different variation as a new option instead. All of the comments from the group were captured and fed into the first draft of the formal consultation document.

At the second meeting held on the 30 July 2014, the group were provided with a copy of the first draft of the consultation document and asked to comment on the content. The group decided that their involvement should extend to reading through the consultation document paragraph by paragraph which they duly did. They looked at each section and checked it for both empathy and to ensure it read easily and in a public friendly way, clear of NHS and BCCG jargon. This piece of work resulted in many changes to the consultation document and the final version fully reflected the views captured by the stakeholder members.

The group themselves then requested a third meeting – held on 30 September, mid-way through the formal consultation process – so that they could be updated on the progress made. During this meeting, they were also able to receive an update on the activities undertaken by BCCG and were able to offer additional suggestions to increase response rate. They looked at some demographic analysis of the responses received so far, identified some gaps and suggested places and organisations that BCCG should visit. They also actively assisted with distributing the consultation document to some of the places that they knew and had suggested.

The stakeholder group were an integral part of the specialist fertility services engagement and consultation and brought some valuable expertise to the project. BCCG were incredibly lucky to be able to recruit such an enthusiastic group of people who have kept up an active involvement in the project as it has progressed. Many of the stakeholders have indicated a desire to be at the Governing Body meeting where a final decision will be made, because they are so keen to see the project through to the end.

The minutes from the Stakeholder meetings can be found in Appendix C.

Distribution of consultation document and completed activities

The formal consultation began on 11 August 2014 and BCCG widely distributed hard copies of the consultation document. The same information was also made available online via BCCG's website and also promoted via some of our local stakeholders, such as Healthwatch and the CVS.

The engagement team at BCCG then undertook a wide range of activities to try to engage members of the public in the consultation process. This included internal staff events, visiting other local, large employers such as Bedford Borough and Central Bedfordshire, stalls in supermarkets and town centre markets as well as attending organised events such as Diwali. The project manager also took up an opportunity to speak on a local radio station to discuss the specialist fertility services consultation,

This engagement work was supported by various communications including press releases, updates on the website and regular tweets.

A list of all completed activities and list of tweets can be found in Appendix D

OSC

As part of the engagement and consultation exercise, it was necessary for the project manager to keep our local Overview and Scrutiny Committees (OSC) involved. Bedfordshire has two such Committees, one for Bedford Borough Council and one for Central Bedfordshire Council. Both committees were very interested in the project and requested to be kept informed of developments. As such the project manager attended twice during the course of the formal consultation to keep the members up to date.

On the second occasion that Bedford Borough OSC received their update, they expressed a few concerns. As process dictates, they expressed these concerns in an official letter in their OSC capacity and BCCG responded accordingly. The OSC were happy with the response provided by BCCG and the consultation continued to progress.

The OSC letter and BCCG response can be found in Appendix E

Survey correction and consultation extension

Once the consultation was well underway, BCCG received a telephone call from a member of staff who worked at Bourn Hall (A local provider for IVF services) who advised there was a tiny typo in the consultation document. The NICE guideline described in the consultation document was incorrect and stated that women aged between 23-39 were entitled to 2 cycles of IVF when, in fact, it should have stated that they were entitled to 3. At the point that BCCG was made aware of the error the documents both online and paper versions, were changed to show the correct information. A statement was also produced and placed online informing the public of the error. This was a genuine error and BCCG were keen to be open and transparent in ensuring the public had the correct information and so could make an informed choice.

With the above in mind, and because the OSC had already raised the issue of the timescale for the consultation, BCCG decided to extend the consultation period by three weeks. This extended the deadline for responses from 3 October to the 31 October.

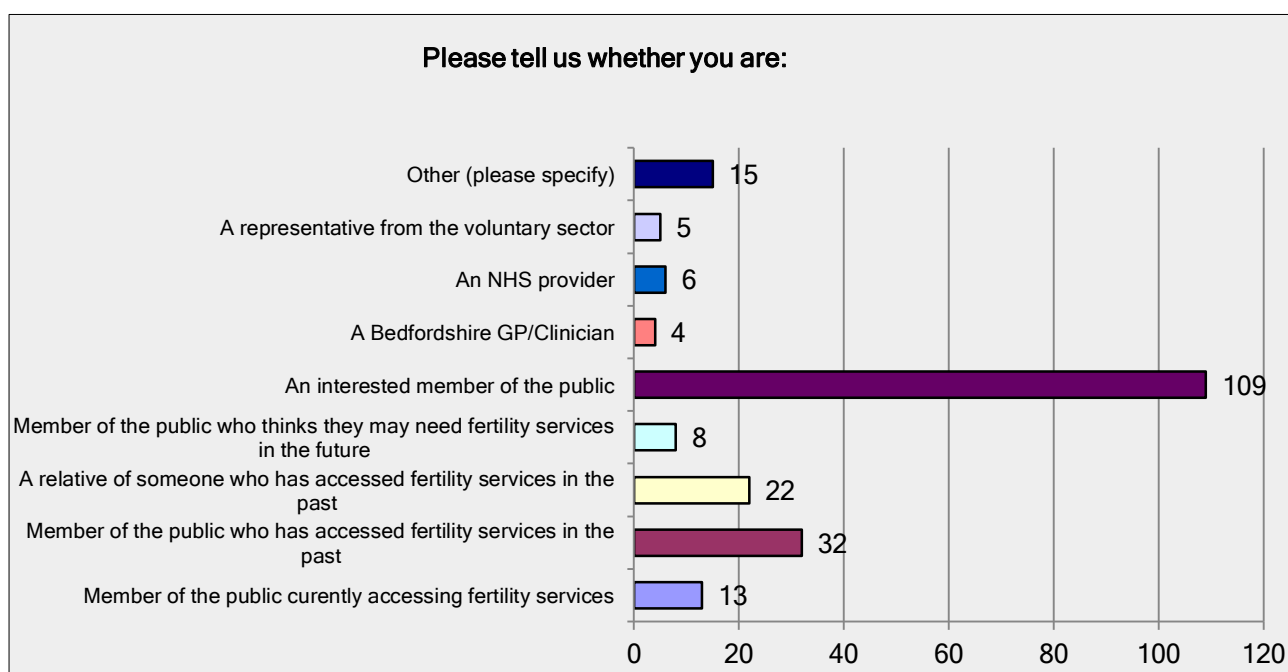
Stakeholder Feedback Analysis

Within the stakeholder meetings, BCCG set themselves an internal target of 150 responses. By the time the consultation closed on the 31 October 2014, 215 had been received - exceeding the target by a third.

Of those 215 responses 128 of those were paper copies and 87 were through the online survey.

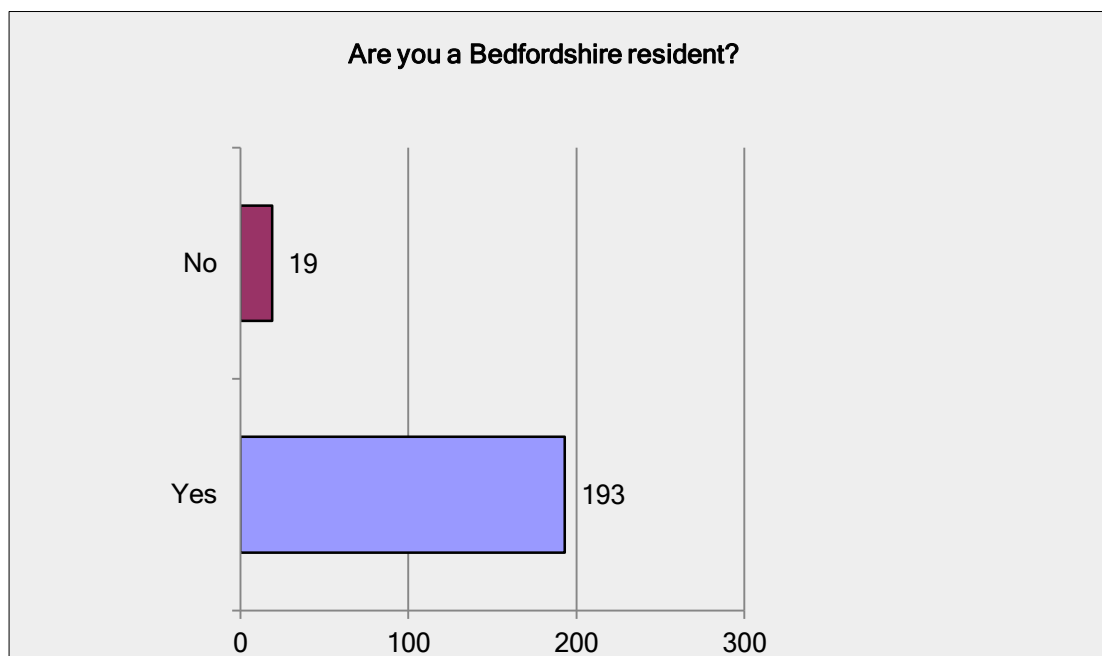
The breakdown of the responses are as follows:

Question 1:



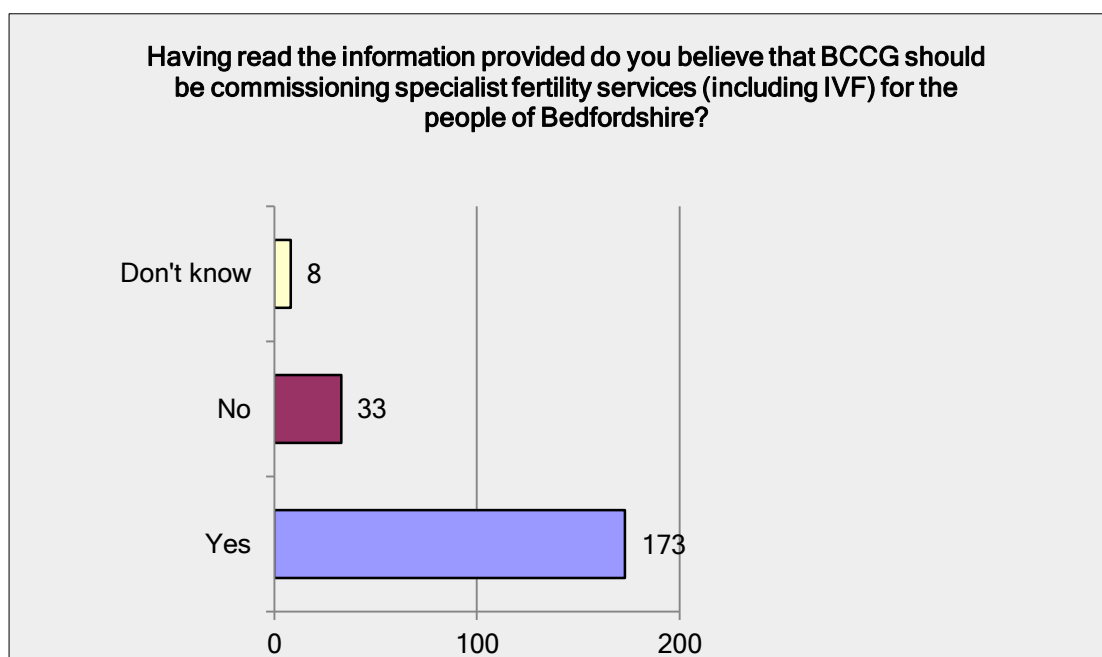
(1 skipped answer = 214 responses)

Question 2:



(3 skipped answers = 212 responses)

Question 3:



(1 skipped answer = 214 responses)

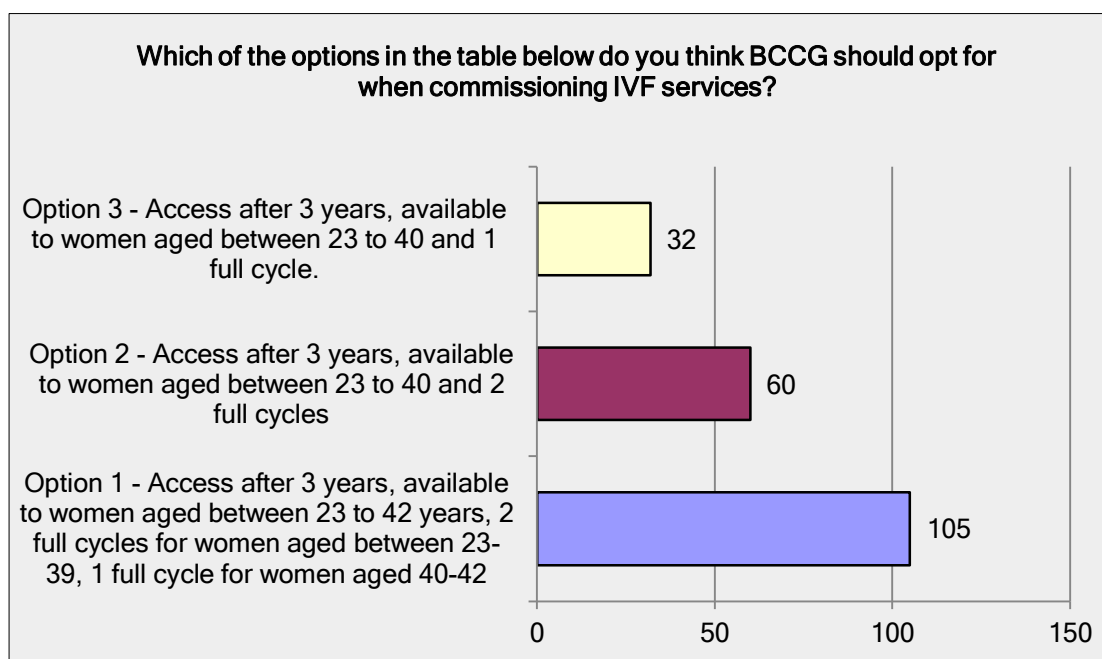
Question 4

Question 4 asked people to explain their reasoning for question 3 about whether or not BCCG should be commissioning specialist fertility services (including IVF). Here is a sample of written responses:

There is nothing in the world like having your own child and if women can be assisted to try to have one, it will bring them and their families the generations, so much happiness and love. The great sadness of not being able to bear your own child is very painful for a woman and her family.
Infertile couples deserve the chance to have a baby.
Unexplained infertility is devastating to a woman who wants a baby.
People can always try and adopt a child as there are plenty of orphans looking for a caring, loving family.
I can only imagine that wanting a child and not being able to conceive is awful.
Having a child is an option and adoption is an alternative. There are thousands of people who desperately need medical attention which is not an option.
Infertility is a medical issue with potentially wide reaching ramifications ie quality of life, mental health. Therefore I feel that a degree of medical care should be available on the NHS.
We are over populated already. If someone can't conceive they should be encouraged to adopt or foster as we also have so many looked after children who need loving families.
In times of such budget constraints I do not feel that infertility is an illness - it is a sad fact of life for some couples for who I have great sympathy. I feel that they should fund their own treatment as there are too many ill & elderly people who do not receive adequate care because of inadequate budgets.
Would prefer budget to be used for other treatments such as cancer or unwell babies.
Its a personal thing between 2 people, if people want a baby should fund themselves. NHS should spend money to make people better.
There is no society need for IVF. It is expensive - so is bringing up children - if people are that keen take a loan out to fund it! The BCCG has not enough money for this as you know!

(157 received responses)

Question 5:



(18 skipped answers = 197 responses)

Question 6:

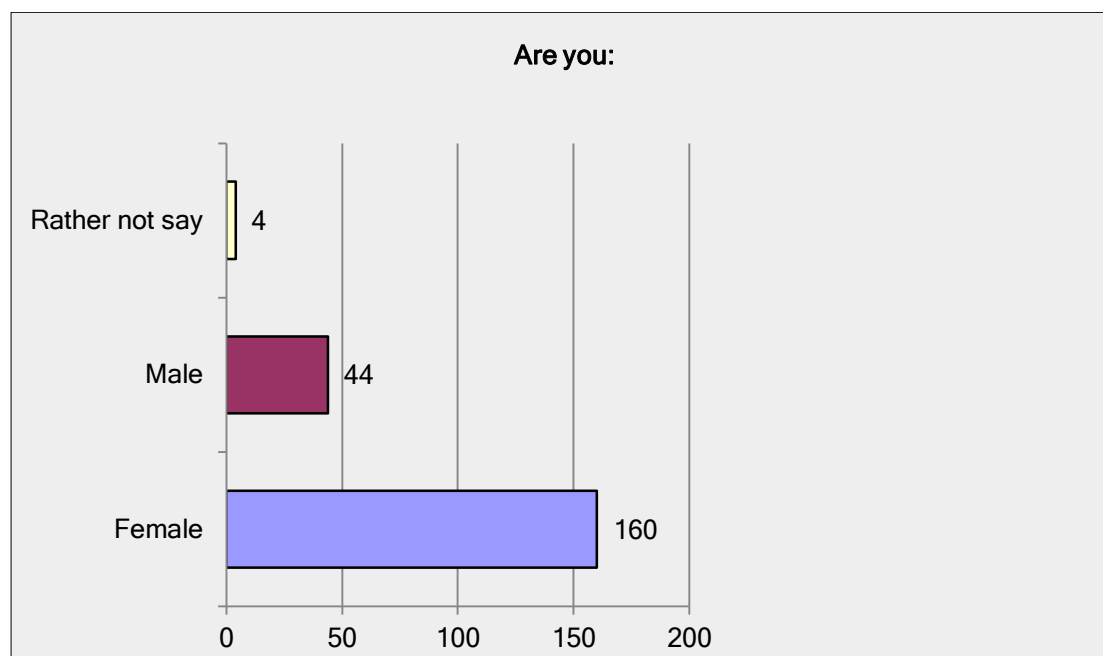
What do you feel is the most important consideration for BCCG when making decisions about the IVF eligibility criteria for the future? (1 high - 5 - low)							
Answer Options	1	2	3	4	5	Rating Average	Response Count
Age Range	58	52	43	21	12	2.34	186
Number of cycles	59	44	42	24	12	2.37	181
Budget	41	37	42	45	16	2.77	181
Access to the service	47	35	40	39	13	2.63	174
Other	18	6	5	3	27	3.25	59

(22 skipped answers = 193 responses)

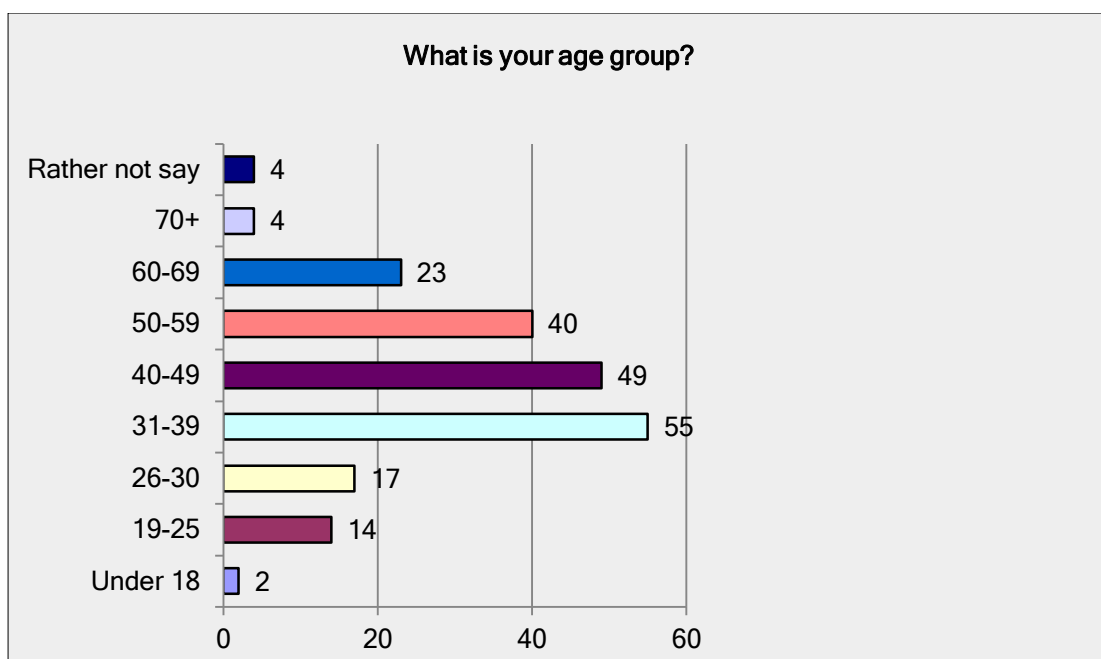
Question 7 asked respondents to make any other general comments on the consultation. Below is a cross section of responses:

My opinion: The age range should be restricted between 30-4-. The problems with children with increased chance of abnormality after 40 year of age.
It may seem frivolous but it takes over your life when you decide you want children and have trouble conceiving.
How to sign-post couples towards other options such as adoption
Shouldn't be on NHS.
Use money elsewhere in health!
I believe it should be available for one cycle. Although failure is a possibility, a couple should be in a financial position to stretch to pay for a second try themselves if they are budgeting to have a child.
Counselling should be provided before and after
Good considering people's feelings and asking for views.
I empathise with the heartbreak infertility brings, but it is not a medical emergency, so offering 1 cycle seems fair, but like cosmetic surgery, it is the wish of the female that is prevailing, not medical reasons. (Obviously this is just my opinion).

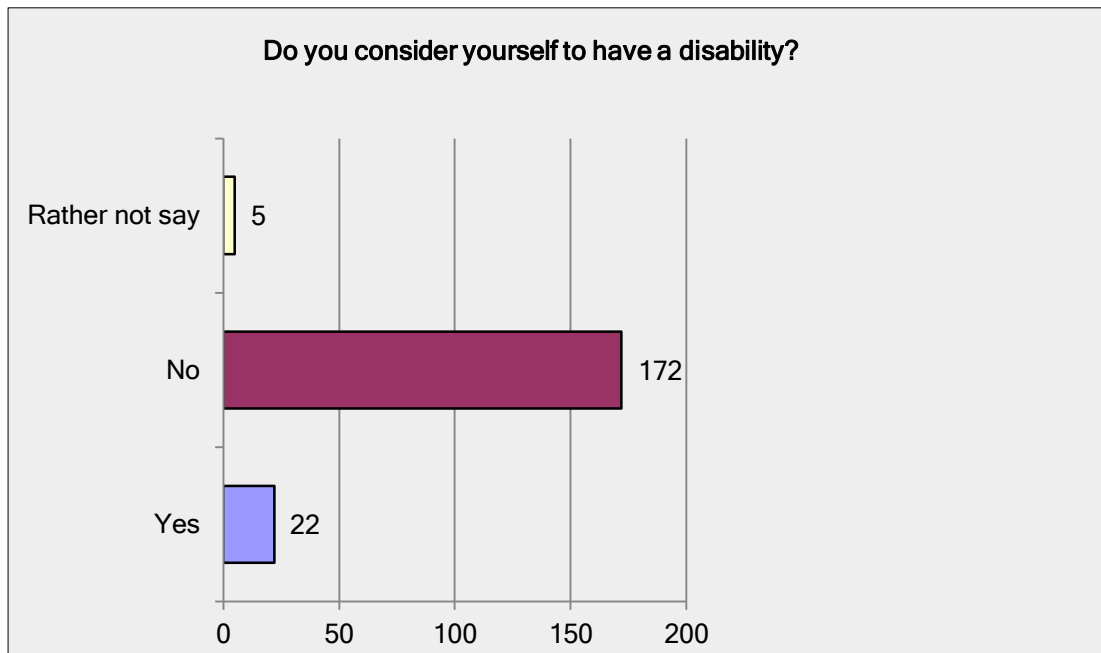
Demographic questions:



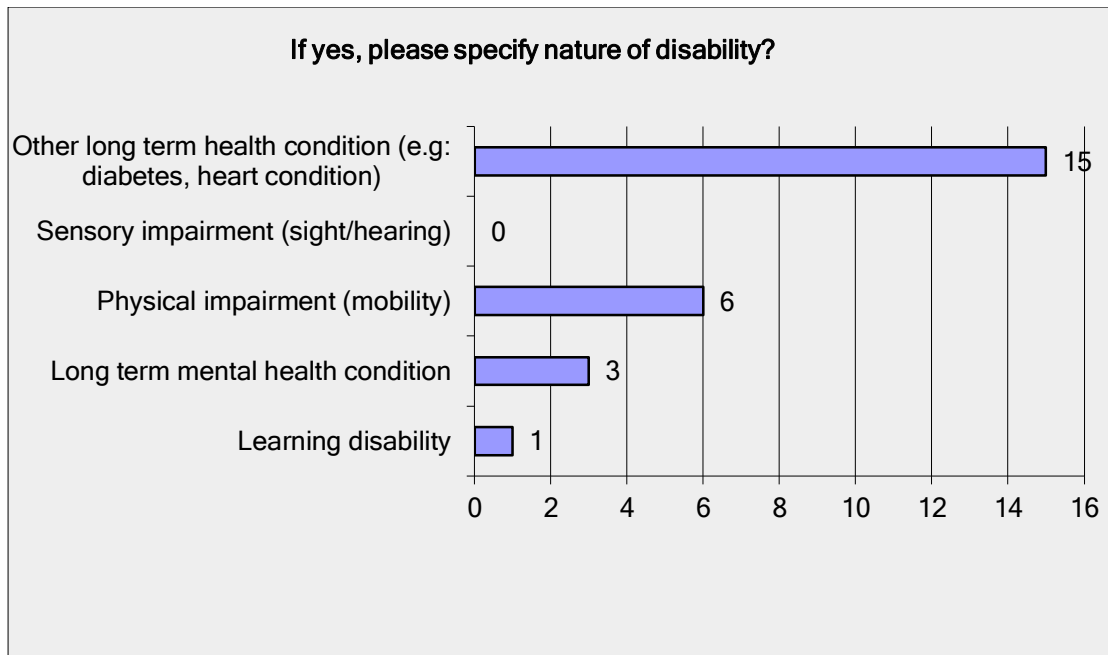
(7 skipped answers = 218 responses)



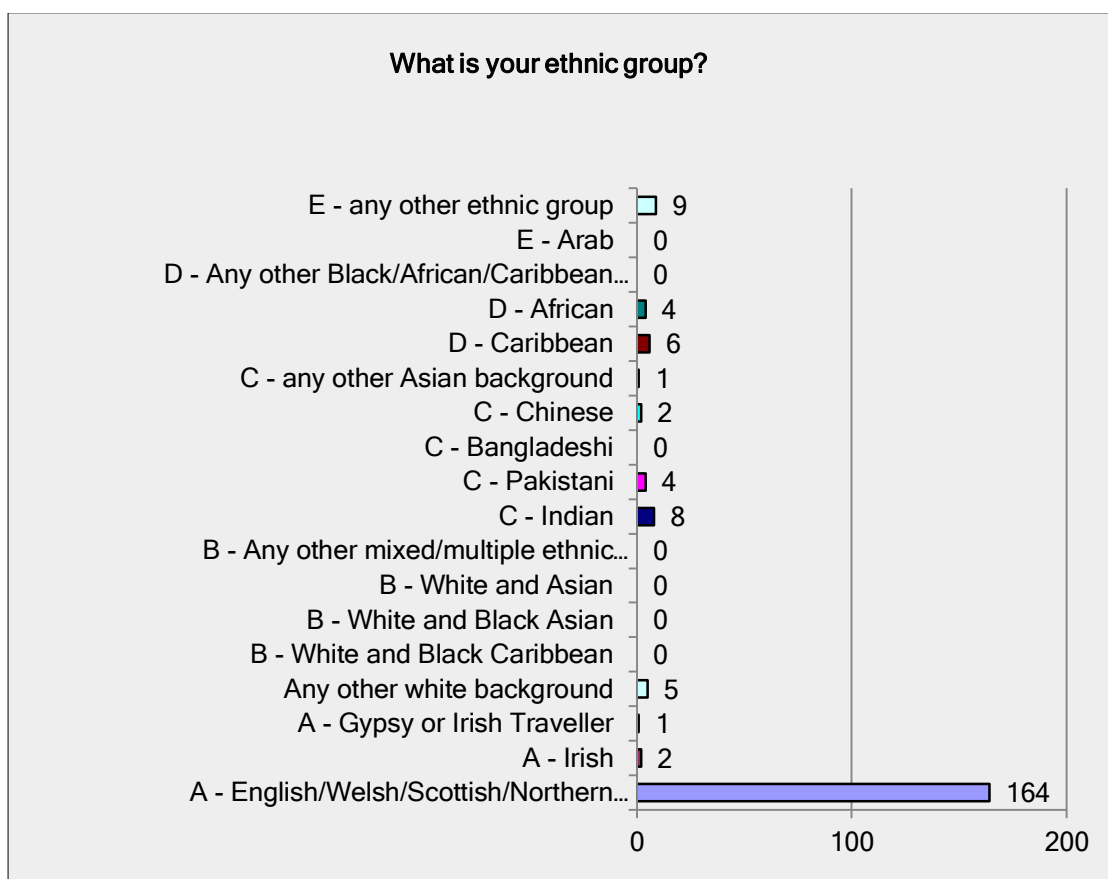
(7 skipped answers = 208 responses)



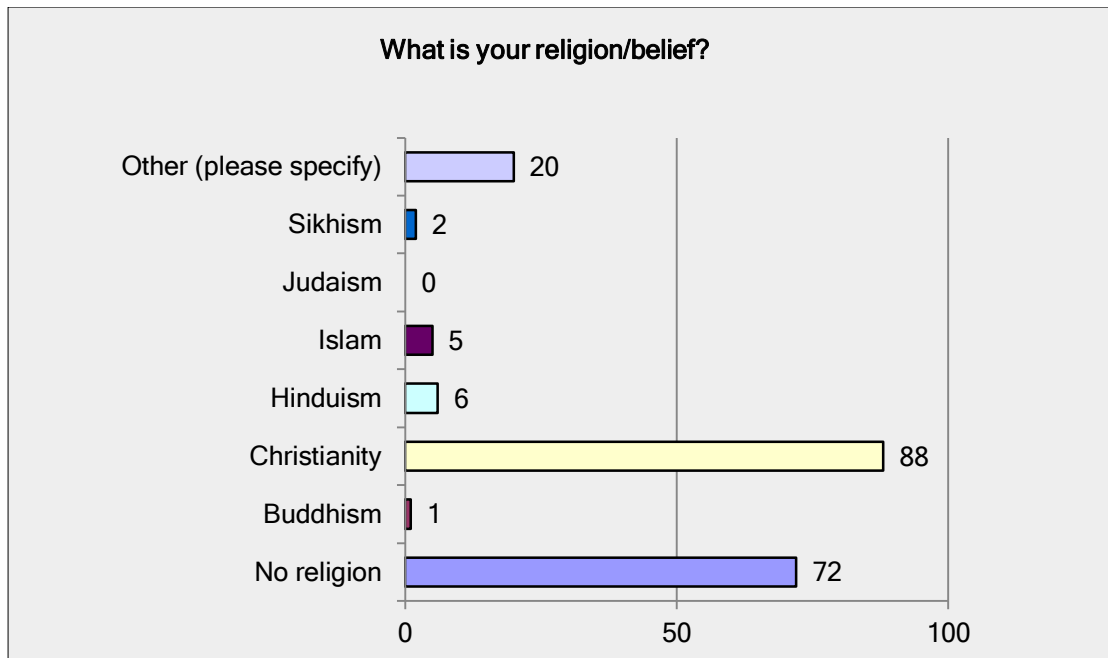
(16 skipped answers = 199 responses)



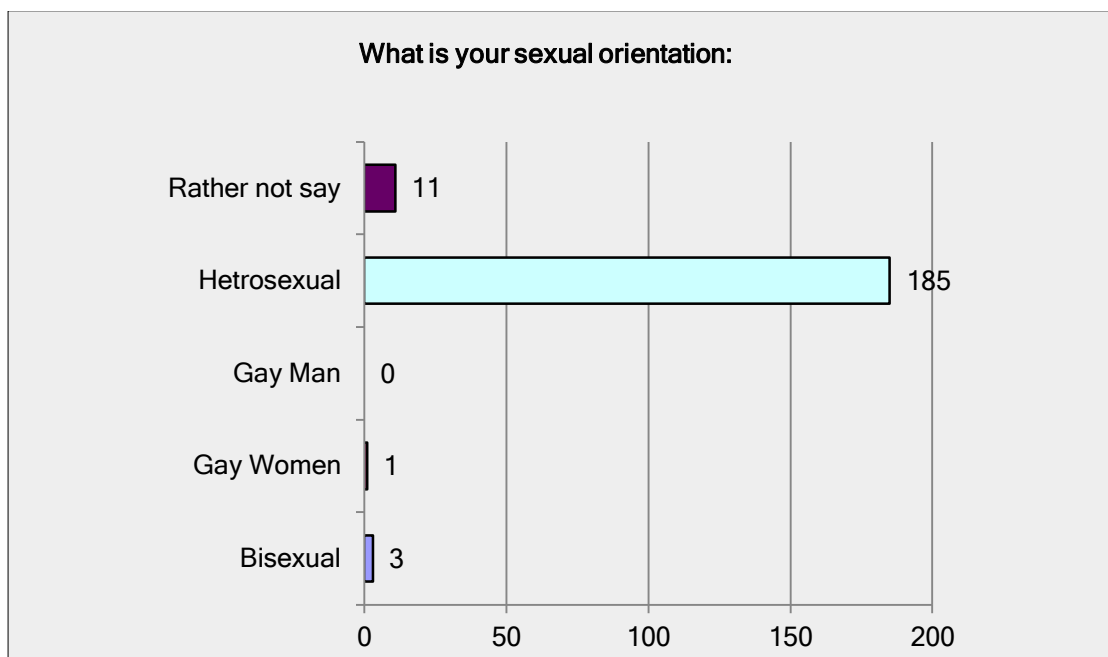
(24 responses)



(9 skipped answers = 206 responses)



(21 skipped answers = 194 responses)



(15 skipped answers = 200 responses)

Key Findings/Summary

Ultimately, the key findings suggest that a broad range of people were provided with the opportunity to feedback their view on specialist fertility services, both past and present patients of the service as well as a large number of general members of the public.

Overall the consultation results show that the majority of respondents felt that BCCG should be offering specialist fertility services (including IVF) on the NHS. When asked directly which option they felt BCCG should commission, the majority of respondents supported the preferred option put forward by BCCG (option 1). Option 2 was the second most popular option followed by option 3.

Next Steps

The formal consultation closed on 31 October 2014. The responses have all been inputted and analysed with the above trends.

This report, along with a final recommendation based on the consultation results, will form part of the agenda for the BCCG's Governing Body in December. This meeting will be held in public and a final decision will be sought.

End

APPENDIX A – Case for Change

Case for Change: Specialist Fertility Treatments Local Criteria

Project Lead: Angelina Florio

1. What is the nature of the proposed change or development or services?

Until March 2013, specialist fertility services were commissioned regionally by the East of England Specialised Commissioning Group (EoE SCG). Since April 2013, individual Clinical Commissioning Groups became responsible for commissioning these services.

Bedfordshire Clinical Commissioning Group (BCCG) has been working with Clinical Commissioning Groups (CCGs) in the East of England to procure region wide specialist fertility service via a collaborative agreement (made up of 19 CCGs within the EoE region).

Whilst the East of England wide collaborative addresses the contractual element of the service i.e. the service providers, it is the responsibility of each CCG to determine their local eligibility criteria and policy that will specify service user access to the service.

In February 2013, the National Institute for Health and Clinical Excellence (NICE) updated their guidance in respect of fertility (CG156, February 2013). The new guidance provides specialist fertility treatments to a certain section of the population for whom it was not previously available to and shortens the waiting time for treatment from 3 years to 2 years.

There are two key changes in the NICE guideline which differ from the existing policy and have a resource implication on BCCG. These are:

- Access to IVF after 2 years rather than 3 years with earlier access for women aged 36 years or over
- Offer one cycle of IVF treatment to women aged 40-42 years

NICE provides various types of national guidance on promoting good health and preventing and treating ill health. The fertility guidance referred to within this report is one that provides recommendations about the treatment and care of fertility. This type of guidance is not mandatory for commissioners to follow and fund its recommendations. This type of guidance is very different from the 'technology appraisal guidance' produced by NICE which is mandatory for CCGs to fund.

2. Patient Journey now

Consultants within secondary care providers e.g. Bedford Hospital and Luton and Dunstable Foundation Trust refer Bedfordshire patients to specialist fertility providers (Barts and London NHS Trust, Bourn Hall Clinic, Imperial College Healthcare NHS Trust and Oxford Fertility Hospitals).

A decision by a Consultant to refer a couple for NHS funded IVF or other fertility service is based on an assessment against the East of England eligibility criteria. The criteria currently in use were developed by the EoE Specialist Commissioning Group in 2011 when it was responsible for the commissioning of specialist fertility services.

The criteria includes the following:

	Waiting time for access to IVF	Age restrictions	Number of cycles
Existing Policy East of England SCG Policy 2011	Access to IVF after 3 years	Aged 23 to 40 years	3 full cycles of IVF

3. Patient Journey in the future

Secondary care providers will continue to refer patients to specialist fertility providers. A decision to refer a couple for NHS funded IVF or other fertility services will be based on an assessment against local Bedfordshire eligibility criteria

that are yet to be determined.

4. Future Commissioning of Specialist Fertility Treatment

Unfortunately all CCGs in the UK find themselves in a very difficult position where the cost of implementing the entirety of the revised fertility NICE guidance is far more expensive than the current fertility expenditure.

BCCG currently spends £799,000 each year on specialist fertility treatments. If BCCG commissions future specialist fertility services in line with all recommendations in the revised NICE guidance, it would need to find an additional £289,000 – an increase of 36% of the current IVF budget. In a climate where additional funding is absent, the reality of implementing the NICE recommendations in their entirety would result in the requirement to decommission health services elsewhere in Bedfordshire.

Clinicians from the East of England collaborative recognised the dilemma faced by CCGs not being in a position to financially afford commissioning the revised guidelines in their entirety. Collectively, they identified a number of alternative potential commissioning options that comprised a variation of elements of the revised NICE guidance along with variations that diverge from the NICE guidelines. The variations within these options are to the number of cycles offered, the age range of women that can access IVF and the number of years waiting time prior to service users accessing IVF.

These discussions further resulted in the identification of a future commissioning option that Clinicians in the EoE considered to be the best value for money option if CCGs were unable to fund the revised NICE guidelines in full. The option includes the following:

	Waiting time for access to IVF	Age restrictions	Number of cycles
Option 1 EoE collaborative recommended option	Access to IVF after 3 years	Aged 23 to 42 years	2 full cycles of IVF treatment for women age 23 to 40 1 full cycle of IVF treatment for women aged 40-42

Clinicians considered the EoE recommended option as the option that is closest to the revised NICE guidelines with the least financial implication. Extending the age range in line with the NICE guidelines enables women aged 40 to 42 to access IVF whilst they previously were excluded. Therefore this option provides opportunity for more of the population to access IVF than the other options and the existing criteria. The majority of CCGs in the East of England have opted for this recommended option.

The table below shows a comparison of options against the existing EoE policy and the revised NICE guidelines. It clearly demonstrates the variations in the costs associated with the options and how option 1 (the recommended option) incorporates the NICE guideline enabling women between the ages of 40 to 42 to access IVF services.

	Waiting time for access to IVF	Age restrictions	Number of cycles	Costs
Existing Policy East of England SCG Policy 2011	Access to IVF after 3 years	Aged 23 to 40 years	3 full cycles	£799,000
NICE CG156, 2013 guidelines	Access to IVF after 2 years with earlier access for women aged 36 years or over	Aged 23 to 42 years	3 full cycles of IVF treatment for women age 23 to 40 1 full cycle of IVF treatment for women aged 40-42	£1,088,000
Option 1 EoE collaborative recommended option	Access to IVF after 3 years	Aged 23 to 42 years	2 full cycles of IVF treatment for women age 23 to 40 1 full cycle of IVF	£650,000

			treatment for women aged 40-42	
Option 2	Access to IVF after 3 years	Aged 23 to 40 years	2 full cycles of IVF	£547,000
Option 3	Access to IVF after 2 years	Aged 23 to 40 years	2 full cycles of IVF	£807,000

Locally, Bedfordshire CCGs executive management team considered the options for future commissioning of IVF in light of the revised NICE guidelines and options proposed by the EoE collaborative. Additional funding for the application of the revised NICE guidance in full is not available. The executive management team therefore considered that the consensus recommendation by the clinicians from the EoE collaborative (Option 1) would also be Bedfordshire CCG's recommended option, given that it increases the availability of IVF to patients whilst remaining in budget and thereby not risking decommissioning of other services. However, the executive management team also recognised the sensitivities of any decisions in this area and the need for consultation with the public before making a final recommendation to the CCG governing body.

5. What engagement has there been and what are the plans for further consultation?

The East of England collaborative has garnered comments, input and opinion from a number of clinicians across the region. Local GPs have actively participated in this process, along with hospital specialists and public health consultants. Much detailed deliberation has taken place considering the future potential commissioning options for IVF in light of the revised NICE guidance.

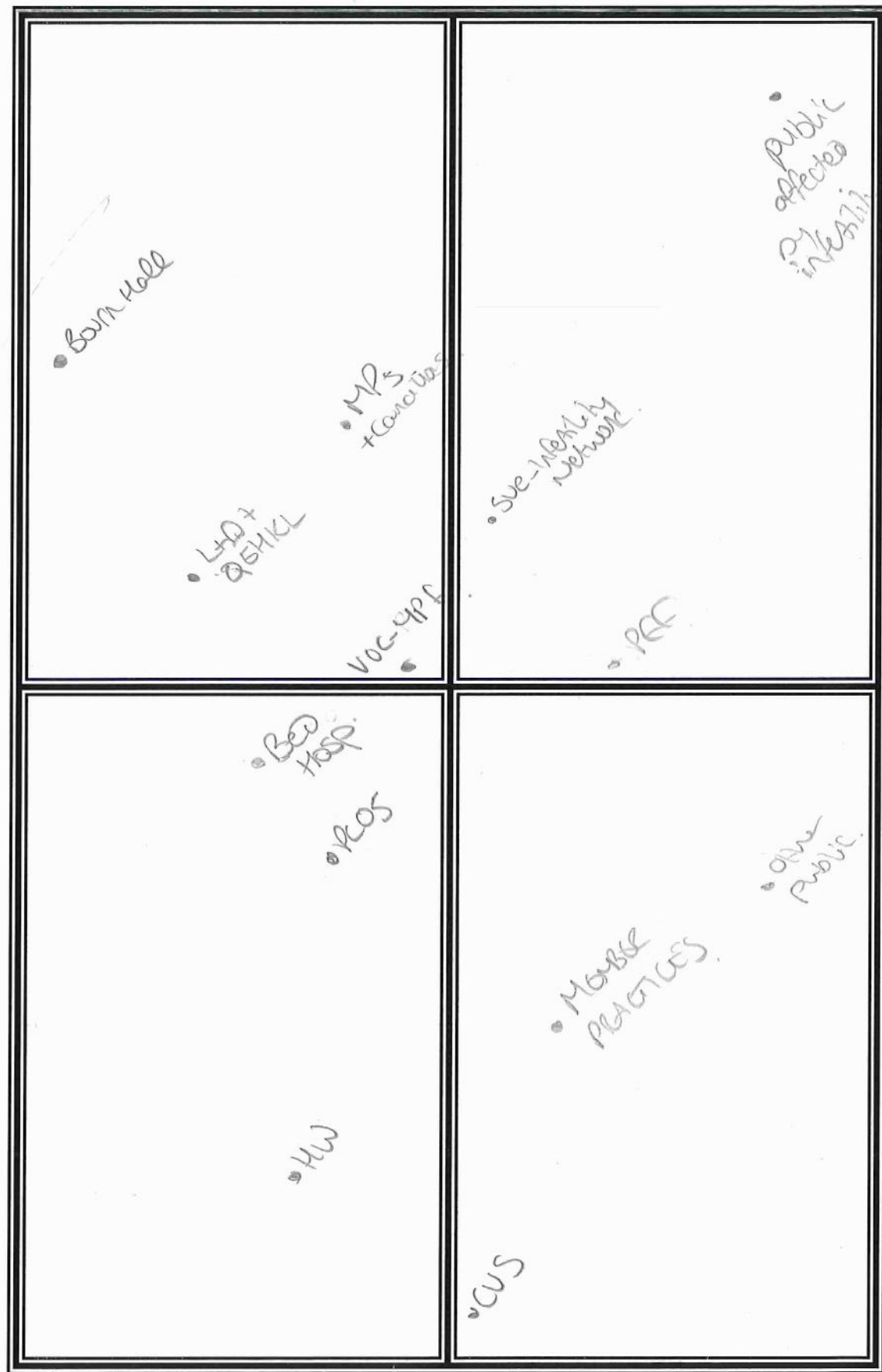
BCCG's executive team has considered the trade-offs required between extending availability to IVF (as per the revised NICE guidance) and the necessary increased funding that full implementation of such guidance would need. Given the potentially sensitive nature of such funding decisions, the CCG plans to consult with the public and other local clinicians on the options as set out in the table, which include the status quo, the recommendation from the EoE collaborative and the full NICE guidance.

BCCG recognises the need for a meaningful and appropriate level of consultation in respect of IVF and has therefore been in discussion with the Consultation Institute (CI). BCCG has been successful in securing a dedicated resource from the CI who would work with BCCG in developing a sensitive but purposeful approach to consulting with patients on this emotive issue. The Consultation Institute would underwrite the BCCGs plans to engage with the local public and further engage with its local clinicians in a consultation process prior to making a decision in respect of its eligibility criteria for Bedfordshire residents, in particularly whether option 1 is the preferred option.

The consultation would start in June 2014 and would last for a period of 6 weeks, after which a final recommendation would be made to the Governing Body in August 2014.

Angelina Florio
System Redesign Manager

Stakeholder Mapping Matrix



High

20150304

Low



IVF Stakeholder Forum

Tuesday 15th July, 2014

House Rules:

1. There is to be one conversation at any given time.
2. There must be a tolerance of the each individual's person views.
3. Give everyone a fair opportunity to speak if they would like to.
4. Mobile phones on silent until the breaks.

Exercise 1:

Without stopping to temper your response, please give us your initial gut reaction.

- I feel that the three options are inflexible and don't meet the needs of this group.
- What clinical criteria are the extending to 42 years made on?
- The rules are too ridged.
- What is the current patient group made up of? E.g. age, variety of treatments etc.
- Would it be possible to divide the age group? Younger age group – wait 3 years, older age group – wait 2 years?
- Cycle vs success rates?
- How flexible is the criteria? Some people will be harmed by a 3 year wait.
- There is no option being considered for 3 cycles.
- Wait time to be flexible, regarding age.
- Woman need more information regarding AQC criteria. They often wait until 30's before attempting to get pregnant.

Initial questions.

- What is the medical significance of increasing the age by 2 years and reducing the cycle by 1?
- Psychologically the impact on the relationship is massive if you have to wait longer for IVF.
- Does IVF include all types of fertility treatments?
- Who decided the age banding?
- There needs to clarification on the different types of cycles, fresh or frozen cycles. I've noticed that some areas count the number of cycles differently depending on if they are fresh or frozen.
- Does IVF money impact on other fertility treatments?
- What age group do men fall into? Is it the same as woman?
- What is the local uptake on IVF and how does this compare nationally?
- What are the differing success rates of accessing IVF after one or two years?
- What happens if you wait 3 years when you are in your late 30's? Surely you fall of the age group?
 - There is a big issue with age constrictions as everyone is different.
- Does it make any difference if you have children already?

- Have all the eligibility criteria been openly available?
- It is worrying that there is no option available with 3 cycles as research proves that your chance of falling pregnant with IVF increases with each cycle.
- Has anyone been very statistical with these options and compared each given option with the potential likely hood of a successful pregnancy?
- Woman who aren't eligible for IVF still go and have hundreds of pounds from the NHS spent on them. Should the criteria from IVF be pulled across to all fertility treatments?
- What fertility support do you give on the NHS for woman? – Ovulation monitoring and IVI. We're hooked on IVF, other services may be better suited.
- There is a pot of money that you could potentially break down and spend more on those who do not have children.
- What happens to the woman who has no children, her partner has a previous child who she the woman has no contact or relationship with. If the woman has no children she should be entitled to IVF. It is a personal right for a woman or a man to have the opportunity to nurture a child.

Exercise 2:

Now think more deeply – are there any other comments you think or feel that you would like to make?

- IVF cannot be set on its own. Other fertility issues need to be taken into account.
- We need to see the full picture and costs.
- If success increased with number of cycles why no 3 cycle option? Change eligibility criteria to accommodate?
- IVF is just one aspect of fertility care and shouldn't be looked into in isolation.
- Are we using the clinics with the highest success rates? Are we following there rates year on year?
- Very emotional issues. Need to make sure that everyone has the same access (i.e. woman and men that live in households with children of their partner but have no biological children of their own).
- Very difficult to make one size fit all.
- Need some consistency in information and action.
- Eligibility criteria should reflect personal circumstances – existing children.
- Difficult to look at IVF in isolation outside of full fertility services.
- There are more procedures surrounding the 'other parts' of IVF, not just the implanting of eggs. This needs to be pulled across to all clinics.

Questions and general comments.

- Funding:
 - Does each area have the same budget?
 - Are we under or over the budget for are area, if we are under do we have any money left?
 - Is funding provided on a year by year basis?
 - Are all IVF centres charging the same per cycle?
- Will woman be restricted to East of England choices?
- Do we know the success rate of the centres? – is it all graded online?

- Not everyone knows that this information is online. It should be sign posted. Could there be leaflets with information to websites?
- Why do centres vary? Is it because they use different procedures?
- Will the consultant refer you to the best clinic?
- Timescale is more of an issue than the actual treatment. Waiting for tests and consultations takes too long.
- If there is any research on age and the chances of falling pregnant under IVF please share.

Number of cycles decreasing.

- We need to know about the success rate at 2 cycles in comparison with the success rates at 3 cycles.
- If you spend more money on other gynaecological procedures that could potential help to conceive without IVF, would we then be saving money that could be moved around?
- Has there been any work done on increasing the age of when you can begin to have IVF from 23 to perhaps 30, then increasing the number of cycles. You could look at the age range that is accessing IVF currently and base it upon those figures.
 - Alternatively keep the age at 40 instead of raising it to 42. Could this then mean the number of cycles stays at 3?
 - IVF in over 40s increases the risk of abnormalities to babies.
- What is the cost of each cycle and the medication needed?
- The group would like to see three cycles and 40 years old to be the cut of point.

Proposed consultation document

Consultation headings

- What do you mean by number 4? Loads of different options.
- I think it should be:
 - What are we doing now?
 - Why do we want to change it?
- All eligibility criteria should be stated (this would help to knock out loads of questions).
 - Need much more information first of all.
- NICE guidelines.
 - In the media NICE guidelines are portrayed as the care you are entitled to receive.
 - Why are we not following these guidelines? – need to make this clear.
 - Show how if we followed NICE that we would have to decommission elsewhere, give examples e.g. cancer/knee operations or whatever it may be.
 - If you start to quote 'this is equivalent to' you may start to distract and weigh people down with irrelevant information.
 - Need to be clear that the cancer/radiotherapy funding will not be touched.
- Is there a postcode lottery? Considering our patients needs and criteria.
 - What if you live 2 streets down, do you get different treatment?
 - Need to be more open and transparent about differing needs. Show if rules are different in other areas or not.
- There needs to be a patient journey, and numbers available.
 - It is important to have the figures of the number of people who access IVF in Bedfordshire.

- Patients will want to know how you can afford to this/not afford to do that.
- Keep the jargon out.
 - More human, simplistic and precise language.
- Are we sure there's no way of changing the age and getting 3 cycles back?
 - This seems the best way forward.
 - If you're going to do it, get the best possible outcomes otherwise it seems like a waste of money.
 - Could this go on the future options? Need to look at the savings possible.
- As an opening statement say what other CCGs are doing. Especially if they are in a worse position than ourselves.
- Data/figures needed:
 - Break down the ages and how many are going through IVF/Ethnic groups.
 - Do we know the statistics for BME and IVF?
- Are you going to set clinics targets?
 - Patients should be able to rate their experience and give feedback.
 - The responses from patients should be considered.
- Don't swamp people with information on this first part.
 - Bullet point facts rather than large paragraphs.
 - It's worth providing a link to a website which could offer further information.
- Avoid who is/isn't entitled to IVF.
- People forget it is about financial sustainability.
 - There needs to be a financial break down into facts and figures.
 - There is only one pot of money, let us know how much money we have and how it is to be disrupted.
- Talk to both those who have and haven't been affected by IVF.
 - IVF may come at the bottom of priorities for the some of the general public.
- There is better value for money in buying a whole system. That's the future.
- Is there a strategy committee for fertility? Would that change fertility?
- There are bigger problems to solve e.g. dementia etc. CCGs do have to prioritise the care.

Consultation questions

- The figures don't make sense, you have more people in the pot for option 2/3.
 - Need to show what the actual figure is. Explain it for everyone.
 - It may be worth putting down what the overall budget is.
- It's worth having NICE guidelines as a comparison.
- What happens with the differential between option 2 and 3?
- Why aren't we doing 3 cycles again?
 - Can't we get the cost of the services down?
 - This needs to be made clear.
 - Instead of making changes could we not just try to save the £25,000 and still provide 3 cycles?
 - Share hospital costs, or change the policies?
- Is all of this not just to tick a box of saying we've had a consultation?
 - How much sway would the consultation have on the options?
- Question 1:
 - Missing – a patient who in the future may think they need IVF?
- Question 2:

- The figures look wrong.
- Question 3:
 - Instead of the most important, why don't you rank in order of importance?
- Question 4:
 - 'Are there any other relevant comments that you would like to make?'

General comments

- There is lots of basic information available that is not reaching people.
 - Very little people actually go through with IVF, often the other fertility treatments work.
 - Advice, support and de-stressing – some of these barriers are basic needs. Once you're into the system the stress of IVF goes up.
 - Need to decrease the stress of the fertility process.
- Counselling.
 - Have to source your own counselling, or attend open evenings.
 - There is a fair amount of support, but it is just voluntary so not accessible for everyone.

Where should we go, who should we talk to?

- Healthwatch – rave bus, could provide leaflets, or a member of the CCG could join.
- GP surgeries – into GP surgeries.
- Hospital gynecology units – good place to be.
- Target groups – different ethnic groups.
- University/colleges.
- Libraries.
- Supermarkets.
- Pharmacies.
- Support groups.
- Over 55s clubs.
- Age UK.
- Gyms.
- Weightwatchers/slimming world. Dieticians.
 - Target those who are trying to meet the eligibility criteria.

Next meeting Wednesday 30th July, 9.30am, Wrest Park.

IVF Stakeholder Forum

Wednesday 30th July, 2014

In attendance from BCCG:	Angelina Florio (AF), Sarah Frisby (SF), Anona Hoyle (AH)
Stakeholders:	DS, KN, LG , MB, PP, RB and SW

1. Stakeholders (the group) introduced themselves, group included representatives from Healthwatch Bedford Borough, Healthwatch Central Bedfordshire, West Mid Beds Locality, PEF, former medical professionals and Bedford Hypnotherapy Centre. (DS was absent from meeting 15/07/14)
2. Purpose of meeting to produce a reader friendly, fit for purpose consultation document regarding eligibility for IVF treatment.
3. The consultation document must contain accurate information, sufficient information to enable the public to make an informed decision, only include the options which will be considered.
4. AF / SF provided a draft document for the group to consider and provide their feedback on. They advised that the points and discussions from the previous meeting had been valuable in helping shape the consultation paper (draft). The draft consultation document incorporates many of the questions and points raised on 15/07/14.
5. The group need to ensure that the final consultation document is not “biased” or “loaded” and contains all the information in order to make an informed choice.
6. The group worked their way through the three documents – main body of consultation document, feedback form, supplementary question and answer session. There were numerous recommendations including changing of text so it was less clinical, removing duplicated information, improving the grammar. The recommended changes are not detailed in this report; they can be found on the second draft version of the consultation document.
7. There were a number of points raised regarding the documents (these are detailed below)
8. Members of group brought a range of press cuttings to the meeting including:
 - HSJ (25/07/14) - Mid Essex CCG considering limiting IVF services to HIV men and cancer patients
 - [Telegraph 25/07/14](#) – single women should pay for IVF treatment

- Daily Telegraph (25/07/14) – Young widow denied IVF by MK CCG

Points raised by during meeting

- I. Document should include statistics - the number of people who access the service each year,, number of pregnancies and number of successful births
- II. Budgets – state was the budget currently and what services we would get if it stayed the same
- III. Question and answer sheet should be included in the consultation document as well as being on-line
- IV. Additional information / documents should be available on-line and on request including:
 - full East of England (E of E) eligibility criteria
 - current policy
 - recommendations of consortium of 19 CCGs
- V. Include a statement saying that if BCCG adopted all the NICE guidelines it would have to take money away from other health services in Bedfordshire
- VI. BCCG must be clear and state it has a preferred option
- VII. The tables of options and current provision should be split and set out clearer
- VIII. Option 4 should be removed if it is not a viable option
- IX. Is option 3 a viable option as it costs more than the current budget? If it is not a viable option it should be removed. **AF to seek advice from Executive Director.**
9. It was agreed the consultation document would be updated following the recommendations
10. Consultation due to commence 11 August 2014
11. Group confirmed they would like to meet again mid consultation



IVF Stakeholder Forum

Wednesday 30th September 2014

In attendance from BCCG:	Angelina Florio (AF), Sarah Frisby (SF), Anona Hoyle (AH), Lindsey McKenzie (LM), Amanda Murrel (AM)
Stakeholders:	DS, LG , MB, PP, RB and SW

SF welcomed all members of the stakeholder group and explained that:

1. The previous meeting (scheduled on 17th September) was postponed as SF and AF were at BBC3 Counties radio being interviewed about the consultation
2. The purpose of meeting was for BCCG to inform the group how the consultation was progressing and to give the group the opportunity to provide their feedback on the consultation so far and make suggestions at this mid-consultation stage.
3. Following discussions with councillors from the local authorities, the end date was extended to 31 October to allow more time for people to participate in the consultation
4. There had been a couple of queries regarding the consultation document
 - A typo was identified on the consultation document where it referred to NICE guidelines. It said that NICE guidelines recommended 2 cycles and it should have said 3.
 - It had been suggested that the averages for the success rates shown in the table in the Q&A section of the document could be misleading.
5. We wanted to be open and transparent about these queries so we:
 - Published a statement on our website and issued a press release detailing the queries and the steps we were taking to address them
 - Produced an amended online version of the document
 - Produced an amended electronic version of the document
 - Updated the hard (paper) copies of the documents
6. Copies of the consultation documents had been:
 - distributed to all GPs, pharmacies and hospitals
 - distributed to libraries, children's centres and both local authorities

- Distributed by local authorities and Fire and Rescue Service to their staff and consultation networks
7. LG advised that she had not seen the consultation document at her GP Practice (Toddington)
 8. Stakeholder members suggested trying to broaden awareness of consultation by:
 - Promoting in gynaecological clinics
 - Sending posters to GP surgeries
 - Promoting at the university and local college
 - Promoting at sports centres, the rugby club, Harpurs Gym and Homebase
 - Encouraging people from BME backgrounds to participate such as the Islamic Centre, ACCM, International Women's Group, Dom Poloski Club, Italian women's group
 - Encouraging representation from BLGBT community
 9. SF explained that once the consultation ended, there would be a period for consideration, and a report produced which would then go to the Executive and a decision made by the Governing Body in December.
 10. SF reminded the group that it was a consultation and not a vote and that the final decision made would be made by the Governing Body after taking due regard to the feedback whilst commissioning services that deliver the best health outcomes for the local population
 11. SF to send members of the group the date of the Governing Body meeting and also send a link to the report once it's published on the website. SF advised that although the meeting was held in public it was not a public meeting. The Governing Body may consider questions from the public if submitted in writing at least 10 days prior to the meeting
 12. AM confirmed that the Consultation Institute would only 'sign off' the consultation as following Best Practice, if it adhered to Best Practice.

APPENDIX D

List of activities for IVF			
Date	Event	Who?	Responsibility
09/07/2014	Meeting with Sue Wilson	Infertility Bedford Group	AF/SF
15/07/2014	Stakeholder Forum	Stakeholder Group	AF/SF
30/07/2014	Stakeholder Forum	Stakeholder Group	AF/SF
11/08/2014	Webpage goes live	General public	SF
11/08/2014	Article in staff news	Internal Staff	SF
14/08/2014	Consultation highlighted in all staff meeting	Internal Staff	SF
14/08/2014	Distribution of hard copies begun (GPs, pharmacies, libraries and childrens centres, local hospitals)	Public and stakeholders	SF
14/08/2014	email with info sent to Voc-ypf (Linda Bulled)	public and stakeholders	SF
14/08/2014	email sent to Healthwatches asking them to put on website	Public and stakeholders	SF
14/08/2014	email sent to PEF members	PEF	SF
15/08/2014	Article in GP news (for staff and patients)	GP/Staff and public	SF
15/08/2014	email sent to members of the governing body, executive team and clinical leads	Staff	SF
15/08/2014	email sent to locality staff	Staff	SF
15/08/2014	email sent to public members	public and stakeholders	SF
15/08/2014	email briefing sent to MPs	MPs	SF
15/08/2014	email briefing sent to Bedford Hospital and L&D	public and stakeholders	SF
15/08/2014	email sent to Sharon Webster (fire and rescue engagement lead)	public and stakeholders	SF
15/08/2014	email Briefing sent to CVS	public and stakeholder	SF
18/08/2014	information sent out via email to Bedfordshire Fire and Rescue membership (and also community messaging service)	public and stakeholders	SF
18/08/2014	email sent to BB engagement lead - Andrew Maslen	public and stakeholders	SF
18/08/2014	email sent to CB engagement lead - Joanne Lang	public and stakeholders	SF
18/08/2014	email sent to Bourn Hall	public and stakeholders	SF

19/08/2014	email sent to social services (adoption and fostering services)	local authority staff	AF
28/08/2014	Hard copies (35) sent to Bourn Hall in response to their email	public and stakeholders	AH
01/09/2014	Hard copies sent to Sue Wilson - Bedford Health Waiting Room	public and stakeholders	SF
03/09/2014	Bedford Market - Wednesday morning/mid-day	public and stakeholders	SF and AH
05/09/2014	Amphill Waitose - Friday afternoon	public and stakeholders	AF and AH
10/09/2014	Bedford Market - Wednesday afternoon	public and stakeholders	AH and HS
11/09/2014	Staff meeting	staff	SF and AH
12/09/2014	press release	public and stakeholders	SF
12/09/2014	correction statement made on website	public and stakeholders	SF
13/09/2014	press release published on the Bedfordshire on Sunday website	public and stakeholders	External
17/09/2014	BBC3 counties radio live interview	public and stakeholders	AF
18/09/2014	Information on IVF published in Times and Citizen newspaper	public and stakeholders	SF
26/09/2014	Pride in Dunstable - Rave Bus/Just Ask (Asda) - Friday	public and stakeholders	AF/AH
23/09/2014	Biggleswade Asda - Tuesday	public and stakeholders	AH
25/09/2014	Information stand at BCCG AGM	public and stakeholders	SF/AH
30/09/2014	Stakeholder Forum	Stakeholder group	ALL
30/09/2014	Hard copies of document hand delivered to Harpur Gym	public and stakeholders	PP (stakeholder)
30/09/2014	Hard copies of document hand delivered to Bedford Rugby Club	public and stakeholders	PP
30/09/2014	Hard copies of document hand delivered to Womens Islamic Centre	public and stakeholders	PP
30/09/2014	Hard copies of document hand delivered to Chamber of Commerce	public and stakeholders	AM (stakeholder)
30/09/2014	Hard copies of document sent to THT/Brook	public and stakeholders	SF
30/09/2014	Hard copies of document sent to PBIC	public and stakeholders	SF
30/09/2014	Hard copies sent to health establishments	public and stakeholders	SF
04/10/2014	Amphill - Older People's Festival (HW Central)	public and stakeholders	SF
04/10/2014	BACF Event - Bedford	public and stakeholders	AH
09/10/2014	Dunstable Sainsburys - Thursday	public and stakeholders	AH
10/10/2014	Bedford Borough Council	public and stakeholders	SF/AH
17/10/2014	Sandy Market Square (Just Ask/Rave Bus) pride in Sandy	public and stakeholders	PJ
24/10/2014	Central bedfordshire council	public and stakeholders	PJ/AH
26/10/2014	Diwali - Festival of Lights, Bedford	public and stakeholders	AH/HS

IVF Tweets

27 October

Our consultation on speciality fertility services, in particular IVF, closes on Friday. Have you had your say yet? <http://ow.ly/DoH2c>

Oct 14

Our consultation on speciality fertility services closes in three weeks, have you had your say yet? <http://bit.ly/1yybopz>

Dave Simpson [@davesimpson21](#) · Sep 30

Great meeting today at [@BCCG5](#) IVF Stakeholder Forum. Have your say before 31 Oct on BCCG Website

NHS Bedfordshire CCG [@BCCG5](#) · Sep 17

We have been talking to [@BBC3CR](#) about our IVF consultation this morning. To give us your views follow this link: <http://goo.gl/3tU46y>

NHS Bedfordshire CCG [@BCCG5](#) · Sep 12

Have you taken part in our IVF consultation yet? If not there's still time, find out more and take part here! <http://bit.ly/1pWpozS>

NHS Bedfordshire CCG [@BCCG5](#) · Sep 10

Once again we're hitting the streets of Bedford Market to talk about the current IVF consultation. Find us from 2-4pm and tell us your views!

NHS Bedfordshire CCG [@BCCG5](#) · Sep 3

You can find us at Bedford Market this lunchtime speaking about the current IVF consultation. We'd love to hear your views, so swing by!



Your ref:
Our ref: ASH OSC/9.9.14/IVF
Contact: Jacqueline Gray
Direct Dial: 01234 228486
Fax:
Email: Jacqueline.gray@bedford.gov.uk

Dear Angelina,

Bedford Borough Council Adult Services and Health OSC: recommendations regarding the Specialist Fertility Treatments Local Criteria

At the committee's meeting of 9 September 2014, the committee made the following recommendations regarding the consultation and proposals for Specialist Fertility Treatments Local Criteria currently out for public consultation by the Bedfordshire Clinical Commissioning Group.

The recommendations are (as at Minute 32):-

Resolved:

- 3 (i) that the consultation period should be extended;
- 3 (ii) it was disappointing that the consultation had not identified the difficulties in consulting at an earlier stage;
- 3 (iii) that women in the 40 to 42 age range should receive a second cycle of IVF treatment.

As these are formal recommendations made by the Committee under its health scrutiny powers, please could you respond within 28 days with the BCCG's response.

If you would like any more information, please do not hesitate to contact Jacqueline Gray, Service Manager (Scrutiny and Member Support) at the address above.

Yours sincerely,

By Email

Cllr Wendy Rider
Chair

Adult Services and Health Overview and Scrutiny Committee

22 September 2014

By email

Strategy & System Redesign
Capability House
Wrest Park
Silsoe
MK45 4HR
Tel: 01525 864430 [5829]
Email: gail.newmarch@bedfordshireccg.nhs.uk
Website: www.bedfordshireccg.nhs.uk

Dear Cllr Wendy Rider,

**Re: Bedford Borough Council Adult Services and Health OSC:
recommendations regarding the Specialist Fertility Treatments Local
Criteria**

Many thanks for your letter dated 9 September 2014 in which you make comments around the consultation for Specialist Fertility Treatments and for the points which you officially raised. We have now had the chance to consider your recommendations, we have taken each point in turn:

3 (i) that the consultation period should be extended

We have taken on board your comments, along with other considerations, and have extended the consultation period until the 31 October 2014. This provides a four week extension to ensure that members of the public have the opportunity to take part and feedback their views.

3 (ii) it was disappointing that the consultation had not identified the difficulties in consulting at an earlier stage

BCCG conducted a period of pre-engagement before the formal consultation commenced. It was acknowledged at this stage that IVF is a very emotive, private subject. On top of this, we are very keen to hear the views of all members of the public, whether they have been affected by infertility or not, as well as potential future patients. This has been tricky, as people tend to only have a strong view on IVF if they have been through IVF themselves, or have known someone who has. Similarly, people only know they need IVF assistance once they have started the process, making it difficult to determine patients of the future. For this reason, we planned a series of different engagement activities. Some of these have worked better than others, but on each occasion where we have felt it hasn't worked so well, we have made changes to try to increase the number of people we speak to and responses we receive. This is considered best practice consultation, to constantly review our processes and to make changes where necessary.



3 (ii) that women in their 40 to 42 age range should receive a second cycle of IVF treatment.

Thank you for this suggestion. This option is not included as part of the NICE guideline, but will be included in our list of gathered responses to be given due regard and consideration before a decision is taken.

We plan to return to the Committee on 16th December 2014 following the BCCG Governing Body's consideration of the consultation.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Gail Newmarch', written in a cursive style.

Dr Gail Newmarch
Interim Director of Strategy and Redesign