Central
Bedfordshire
Council
Priory House
Monks Walk
Chicksands,
Shefford SG17 5TQ

TO EACH MEMBER OF THE
SOCIAL CARE, HEALTH & HOUSING OVERVIEW & SCRUTINY COMMITTEE

09 December 2014

Dear Councillor

SOCIAL CARE, HEALTH & HOUSING OVERVIEW & SCRUTINY COMMITTEE - Monday 15 December 2014

Further to the Agenda and papers for the above meeting, previously circulated, please find attached the following additional report(s):-

10. IVF Procurement of Services

To consider and comment on the outcomes of the IVF procurement process.

14. Customer Feedback - Complaints, Compliments Annual Report

To receive the Customer Feedback annual report attached as an appendix.

Should you have any queries regarding the above please contact the Overview and Scrutiny Team on Tel: 0300 300 4196.

Yours sincerely

Paula Everitt
Scrutiny Policy Adviser
email: paula.everitt@centralbedfordshire.gov.uk

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Meeting: **Name of Overview and Scrutiny Committee**

Date: **15th December 2014**

Subject: Specialist Fertility Services Local Criteria

Report of: **Dr Gail Newmarch, Executive Member for Bedfordshire CCG**

Summary: This paper presents the outcome of the formal Specialist Fertility Service (SFS) consultation undertaken by Bedfordshire Clinical Commissioning Group (BCCG) along with the decision made by the Governing Body in respect of the local criteria.

Advising Officer:	Dr Gail Newmarch, Executive Member for Bedfordshire CCG
Contact Officer:	Angelina Florio, Head of System Redesign – Adults and Older People
Public/Exempt:	Public
Wards Affected:	All
Function of:	Council

CORPORATE IMPLICATIONS

Council Priorities:

1. This briefing note provides an update following the report Bedfordshire Clinical Commissioning Group (BCCG) submitted to the committee in August 2014. It presents the outcome of BCCG's governing body decision around specialist fertility services (SFS) including IVF in Bedfordshire.

Financial:

2. As a clinical commissioning group we are obliged to ensure we get the best possible outcomes for local people with the money we have available.

Legal:

3. No legal implication.

Risk Management:

4. Not applicable.

Staffing (including Trades Unions):

5. Not Applicable.

Equalities/Human Rights:

6. The decision outlined in this paper does not alter the equality impact of this service.

Public Health

7. Public Health participated in the discussions held with the collaborative agreement.

Community Safety:

8. Not Applicable.

Sustainability:

9. Not Applicable.

Procurement:

10. Not applicable.

RECOMMENDATION(S):

The Committee is asked to:-

1. Note the decision made by the BCCG Governing Body.

Background

11. Until March 2013, specialist fertility services were commissioned regionally by the East of England Specialised Commissioning Group (EoE SCG) when individual Clinical Commissioning Groups (CCGs) became responsible for commissioning these services. Since then, BCCG has been working with 19 other CCGs in the East of England to procure SFS through a collaborative agreement. This agreement currently includes common eligibility criteria for IVF developed by EoE SCG in 2011.

12. However, updated guidance on fertility services published by the National Institute for Health and Clinical Excellence in February 2013[1] has encouraged BCCG and CCGs across the country to reconsider eligibility criteria for IVF. As a result BCCG's governing body has decided that from January 2015 BCCG will**: provide access to IVF after 3 years of unexplained infertility, offering 1 full cycle of IVF treatment for women aged 23 to 39 years**.

13. The governing body took account of the following in coming to this decision:
    - clinical evidence around the effectiveness of IVF
    - the outcome of a public consultation exercise conducted during the autumn of 2014
    - affordability – including the impact that increasing access to IVF might have on other services for Bedfordshire patients.

Current SFS in Bedfordshire

[1] CG156, February 2013

14. BCCG currently spends £799,000 each year on specialist fertility treatments. In 2013/14, BCCG commissioned 243 cycles of IVF across the whole of Bedfordshire. This equates to about 80 patients each year.

15. Hospital consultants at our local providers (for example, Bedford Hospital and Luton & Dunstable Hospital) refer Bedfordshire residents to specialist fertility providers including Barts and London NHS Trust, Bourn Hall Clinic, Imperial College Healthcare NHS Trust and Oxford Fertility Hospitals. They currently base their decision to refer prospective parents for NHS funded IVF based on an assessment against the East of England eligibility criteria. These criteria can be found in appendix 1; and include the following:

16.

	Waiting time for access to IVF	**Age restrictions**	**Number of cycles**
East of England SCG Policy 2011	Access to IVF after 3 years of unexplained infertility	Aged 23 to 39 years	3 full cycles of IVF

17. NICE guidance for access to fertility treatment includes three suggested access criteria that have resource implications for CCGs:

18.
- Access to IVF after 2 years rather than 3 years with earlier access for women aged 36 or over.
- Offer one cycle of IVF treatment to women aged 40-42 who have not conceived after 2 years providing they meet specific criteria.
- Use of single rather than double embryo transfers.

19. If BCCG were to commission future specialist fertility services in line with the entirety of the revised NICE guidance, it would require an additional £289,000. This represents an uplift in funding for IVF of more than one third - 36.170%.

Clinical evidence

20. As a GP led commissioning group, BCCG has looked carefully at the clinical evidence for offering IVF and used that in its decision to alter the access criteria for these services in Bedfordshire.

21. IVF does not always result in pregnancy. In the UK, around 20-25% of IVF treatment cycles result in a birth.

22. The success rate of IVF depends on the age of the woman undergoing treatment as well as the cause of the infertility (if it's known). Younger women are more likely to have healthier eggs, which increases the chances of success. Success rates decrease dramatically in women over 40.

23. In 2010, the percentage of IVF treatments that resulted in a live birth (the success rate) was:

24.
- 32.2% for women under 35
- 27.7% for women aged 35-37
- 20.8% for women aged 38-39
- 13.6% for women aged 40-42
- 5% for women aged 43-44
- 1.9% for women aged over 44

(NHS Choices website)

Formal consultation

25. While infertility affects a small cohort of the Bedfordshire population, the matter could be extremely emotive for those residents that are affected. While some CCGs have decided to decommission SFS altogether, BCCG decided to involve local people in the decision by undertaking a formal consultation process. We did this under the guidance and supervision of the Consultation Institute and by taking feedback from Central Bedfordshire and Bedford Borough Health Overview and Scrutiny Committees.

26. Appendix 2 provides a full report on the consultation which included pre-consultation activity, formal consultation and a consideration phase. As a result of feedback from Bedford Borough HOSC, the consultation phase was extended by four weeks to enable more people to respond.

27. A survey, which formed a key part of the process, gave local residents the opportunity to say whether they thought IVF should be available on the NHS at all. It also offered three possible options for changing the eligibility criteria for Bedfordshire residents.

28. Two hundred and fifteen (215) people responded to the survey – they included members of the public and local clinicians. The majority favoured retaining NHS funded IVF services by 4:1. Respondents also tended to support wider access to IVF as set out in option 1 below.

29.

	Waiting time for access to IVF	Age restrictions	Number of cycles	Cost per year
Option 1	Access to IVF after 3 years of unexplained infertility	Aged 23 to 42 years	2 full cycles of IVF treatment for women age 23 to 39 1 full cycle of IVF treatment for women aged 40-42	£650,000
Option 2	Access to IVF after 3 years of unexplained infertility	Aged 23 to 39 years	2 full cycles of IVF	£547,000
Option 3	Access to IVF after 3 years of unexplained infertility	Aged 23 to 39 years	1 full cycle of IVF treatment	£397,000

30. However, a significant minority of respondents expressed strong views against NHS funding for IVF. Several expressed the view that there was no societal need for IVF but there was a need for more adoption and fostering. Others felt the money could be better spent on other services including cancer care.

Ensuring affordability and value for money

31. As a clinical commissioning group we are obliged to ensure we get the best possible outcomes for local people with the money we have available.

32. When BCCG took the decision to consult, we made it clear that we favoured the more generous criteria offered in option one. Our understanding of our financial position at the time meant that we believed we could extend access to IVF to local people while remaining within budget. However, as explained in another paper to this committee, our financial position has considerably worsened since then. We are currently reporting that we are likely to end the financial year with a deficit of around £25m and are in what is called 'turnaround' to bring CCG finances back on track. This will mean taking some difficult decisions and as a result, it is likely that any decision to extend access to IVF would have a detrimental effect on other services.

BCCG Governing Body decision

33. At its meeting on 3 December 2014, BCCG Governing Body approved a change to IVF eligibility criteria as set out in Option 3 of the consultation survey.

34.

Option 3	Access to IVF after 3 years of unexplained infertility	Aged 23 to 39 years	1 full cycle of IVF treatment

35. In doing so it took account of:

36.
- The clinical evidence around the success of this form of fertility treatment. The governing body accepted that this was a life changing treatment for some families and wanted to continue offering the service to those most likely to benefit. We have also noted that several respondents to the consultation survey highlighted the importance of providing good quality counselling to prospective parents going through IVF.

37.
- The views of local residents and clinicians – the Governing Body noted that there was considerable support for continuing IVF but not everyone believed it should be available for free via the NHS.

38.
- Affordability and value for money – the Governing body noted that was vital that, as clinical commissioners, BCCG provided high quality, affordable care. It accepted that the decision not to extend IVF to a wider range of women was a difficult one but noted that it also had to consider the impact of funding more generous IVF eligibility criteria on other services for people in Bedfordshire

Recommendation

39. The Overview and Scrutiny Committee is asked to note the decision made by the BCCG Governing Body.

Appendices:

Appendix 1 – East of England Fertility Policy

Fertility_Services_Commissioning_Policy_Fi

Appendix 2 - Specialist Fertility Services Consultation Report

Consultation Report - 31 10 14.pd

Appendix 1

East of England
Specialised Commissioning Group

Fertility Services Commissioning Policy

Author:	C Young, Associate Director (Acute Services), East of England Specialised Commissioning Group
Version No:	**3**
Policy Effective from:	1 June 2011
Review Date:	March 2012

This policy replaces all previous versions. Where patients have commenced treatment in any cycle prior to this version becoming effective, they are subject to the eligibility criteria and scope of treatment set out in the relevant version.

Previous versions of this policy:

Version 1 – Effective 15 August 2008 to 30 June 2010
Version 2 – Effective 1 July 2010 to 31 May 2011
Version 3 – Effective 1 June 2011 until review

Document Reader Information

Policy HR/Workforce Management Planning Clinical	Estates Performance IM&T Finance Partnership Working
Document Purpose	Policy
EOE Reference Number	EOESCG FS011
Title	Fertility Services Commissioning Policy
Author	Associate Director Commissioning, Acute Services, East of England Specialised Commissioning Group
Publication Date	1st June 2011
Target Audience	PCTs, NHS Trusts, SHA directors, commissioners, directors of finance, GPs, fertility nurses, service users
Circulation List	All of the above
Description	The EOESCG Commissioning Policy for Fertility Services
Cross Reference	EOESCG Fertility Services Specification NICE Guideline CG011 Towards the best, together. NHS East of England (2008)
Superseded Docs	Individual PCTs documentation in the EOE commissioning fertility services
Action required	For dissemination within primary and secondary care providers
Contact details	C Young Associate Director Commissioner; Acute Services EoE SCG (Satellite Office) Charter House Parkway Welwyn Garden City Hertfordshire AL8 6JL

Contents

Fertility treatment and referral criteria for tertiary level assisted conception

1. Introduction

1.1.1 This Commissioning Policy sets out the criteria for access to NHS funded specialist fertility services for the population of the east of England, along with the commissioning responsibilities and service provision.

1.1.2 This policy is specifically for those couples who do not have a living child from their current or any previous relationships, regardless of whether the child resides with them. This includes any adopted child within their current or previous relationships; this will apply to adoptions either in or out of the current or previous relationships.

1.1.3 The paper specifically sets out the entitlement and service that will be provided by the NHS for In Vitro Fertilisation (IVF) and Intracytoplasmic Sperm Injection (ICSI).These services are commissioned by the East of England Specialised Commissioning Group and provided via tertiary care providers.

1.1.4 This policy also supports the commitment made in the east of England clinical vision *Towards the best, together* to increase the overall number of NHS- funded IVF cycles against standard criteria.

1.1.5 It is the purpose of the criteria set out in this policy to make the provision of fertility treatment fair, clear and explicit. This paper should be read in conjunction with:

- The NICE Guidance CG011 "Fertility: assessment and treatment for people with fertility problems"(2004) available on their website at www.nice.org-pdfCG011niceguideline.pdf.url
- The Human Fertilisation & Embryology Authority (HFEA) document "The Best Possible Start to Life" (2007) available on their website www.hfea.gov.uk
- The report "One Child at a Time" published by the Expert Group on Multiple Births after IVF set up by HFEA available on their web site www.hfea.gov.uk/en/505.html

1.2 Review

1.2.1 The East of England Specialised Commissioning Group will review this policy annually and within 3 months of any legislative changes that should or may occur in the future. The date of the next review will be March 2012.

2. Commissioning responsibility

2.1.1 Specialist fertility services are considered as Level 3 services or tertiary services. Preliminary Levels 1 & 2 are provided and commissioned within primary care and secondary services such as acute trusts. To access Level 3 services the preliminary investigations should be completed at Level 1 & 2.

2.1.2 Formal IVF commissioning arrangements will support the implementation of this policy including a contract between the East of England Specialised Commissioning Group and each tertiary centre. Quality Standards and clinical governance arrangements will be put in place with these centres, and outcomes will be monitored and performance managed in accordance with the Human Fertilisation & Embryology Authority Licensing requirements or any successor organisations.

2.1.3 This policy is specifically for those couples who do not have a living child from their current or any previous relationships, regardless of whether the child resides with them. This includes any adopted child within their current or previous relationships; this will apply to adoptions either in or out of the current or previous relationships.

2.1.4 Couples who do not meet the criteria and consider they have exceptional circumstances should be considered under the Exceptional Treatment Policy of their local Primary Care Trust.

2.1.5 Couples will be offered a choice of providers that have been commissioned by the East of England Specialised Commissioning Group.

3. East of England Fertility services policy and criteria

3.1 Treatments funded

3.1.1 The East of England SCG only commissions the following fertility techniques regulated by the Human Fertilisation & Embryology Authority (HFEA).

3.2 In-Vitro Fertilisation (IVF)

3.2.1 An IVF procedure includes the stimulation of the women's ovaries to produce eggs which are then placed in a special environment to be fertilised. The fertilised eggs are then transferred to the woman's uterus.

3.2.2 For couples requiring IVF or ICSI, this policy supports a maximum of 6 embryo transfers with a maximum of three fresh cycles, this includes abandoned cycles. Where couples have previously self funded an IVF

cycle without PGD and pronucleate or cleavage stage frozen

embryos (not blastocysts) exist, then the couples must utilise the previously frozen embryos, rather than undergo ovarian stimulation, egg retrieval and fertilisation again.

3.2.3 An embryo transfer is from egg retrieval to transfer to the uterus. The fresh embryo transfer would constitute one such transfer and each subsequent transfer to the uterus of frozen embryos would constitute another transfer. In all fresh cycles for women under the age of 37 years of age only one embryo, or blastocyst, will be transferred, unless there are medical mitigating circumstances.

3.2.4 A fresh cycle would be considered completed once administration of drugs for the purpose of superovulation has occurred, or if no drugs are used, with the attempt to collect eggs.

3.2.5 For couples where the woman is under 38 years of age, there should be a six month period between completion of the pregnancy test and commencement of drugs for the next fresh cycle.

3.2.6 If a cycle is commenced and ovarian response is poor, a clinical decision would need to be taken as to whether a further cycle should be attempted, or if the use of a donor egg may be considered for further IVF cycles.

3.2.7 Couples will be advised at the start of the treatment that this is the level of service that is available on the NHS in the East of England and that the NHS will fund storage of the embryos for one year only. Patients must be counselled by the clinician and infertility counsellor to this effect. Any costs relating to the continued storage of the embryos beyond the first calendar year of the retrieval date is the responsibility of the couple.

3.2.8 If any fertility treatment results in a live birth, then the couple will no longer be considered childless and will not be eligible for further NHS funded fertility treatments, including the implantation of any stored embryos. Any costs relating to the continued storage of the embryos beyond the first calendar year of the retrieval date is the responsibility of the couple.

3.3 Sperm Recovery and Intra-Cytoplasmic Sperm Injection (ICSI)

3.3.1 Spermatozoa can be retrieved from both the epididymis and the testis using a variety of techniques with the intention of achieving pregnancies or couples where the male partner has obstructive or non-obstructive azoospermia. Sperm recovery is also used in ejaculatory failure and where only non-motile spermatozoa are present in the ejaculate.

3.3.2 In obstructive azoospermia, sperm needs to be obtained directly from the testis by aspiration (TESA) or biopsy (TESE). In some men sperm

can be recovered from naturally occurring spematoceles by percutaneous puncture.

3.3.3 In non obstructive azoospermia, sperm needs to be obtained directly from the testis by aspiration (TESA) or biopsy (TESE). The chance of finding sperm is reduced. PESA and TESA can be performed under local anaesthesia in an outpatient clinic. Percutaneous epididymal Sperm Aspiration (PESA) does not jeopardise future epididymal sperm retrieval.

3.3.4 Sperm recovery techniques outlined in this section are not available to patients who have undergone a vasectomy.

3.4 Intra Uterine Insemination (IUI)

3.4.1 Due to poor clinical evidence, IUI will only be offered under exceptional circumstances.

3.5 Donor insemination

3.5.1 Male infertility affects about 25% of couples. Until ICSI became available the main technique for treating male factor infertility where azoospermia or severe abnormalities of semen quality were present was insemination with donated sperm. The need to prevent transmission of sexually transmitted diseases (including HIV) by donor insemination has led to the mandatory quarantine of donor sperm for six months by cryopreservation prior to its use in the UK. Donor insemination may be indicated where the male partner is likely to pass on an inheritable genetic condition or severe rhesus incompatibility has been a problem because of the male partners homozygous status.

3.6 Egg and Sperm storage for patients undergoing cancer treatments

3.6.1 The procedures recommended by the Royal College of Physicians and the Royal College of Radiologists should be followed before commencing chemotherapy or radiotherapy likely to affect fertility, or management of post- treatment fertility problems.

3.6.2 Men and adolescent boys preparing for medical treatment, that is likely to make them infertile, should be offered semen cryostorage because the effectiveness of this procedure has been established.

3.6.3 Local protocols should exist to ensure that health professionals are aware of the values of semen cryostorage in these circumstances, so that they deal with the situation sensitively and effectively.

3.6.4 Women preparing for medical treatment that is likely to make them infertile should be offered oocyte or embryo cryostorage as appropriate if they are well enough to undergo ovarian stimulation and egg collection, provided that this will not worsen their condition and that sufficient time is available.

3.6.5 Following cancer treatment, couples seeking fertility treatment must meet the defined eligibility criteria.

3.7 Egg donation where no other treatment is available

3.7.1 The patient may be able to provide an egg donor; alternatively the patient can be placed on the waiting list, until an altruistic donor becomes available. If either of the couple exceeds the age criteria prior to a donor egg becoming available, they will no longer be eligible for treatment.

3.7.2 This will be available to women who have undergone premature ovarian failure due to an identifiable pathological or iatrogenic cause before the age of 40 years or to avoid transmission of inherited disorders to a child where the couple meet the other eligibility criteria.

3.8 Pre-implantation Genetic Diagnosis (PGD)

3.8.1 This policy does not include pre-implantation genetic screening as it is not considered to be within the scope of fertility treatment. The separate East of England Specialised Commissioning Group policy should be referred to when considering PGD.

3.9 Chronic Viral Infections

3.9.1 The need to prevent the transmission of chronic viral infections, during conception, such as HIV, Hep C etc requires the use of ICSI technology. This is a specialist service and is only available at a limited number of centres. The East of England Specialised Commissioning Group commission these services from an appropriately designated unit.

3.9.2 This may not be a fertility treatment, but should be considered as a risk reduction measure for a couple who wish to have a child, but do not want to risk the transmission of a serious pre-existing viral condition to the woman and therefore potentially her unborn baby.

3.10 Privately funded care

3.10.1 This policy covers NHS funded fertility treatment only. For clarity, Patients will not be able to pay for any part of the treatment within a cycle of NHS fertility treatment. This includes, but is not limited to, any drugs (including drugs prescribed by the couple's GP), recommended treatment that is outside the scope of the service specification agreed with the Secondary or Tertiary Provider or experimental treatments.

3.10.2 Where a patient meets the East of England eligibility criteria but agrees to commence treatment on a privately funded basis, they may not retrospectively apply for any associated payment relating to the private treatment.

3.11 Surrogacy

3.11.1 Surrogacy is not commissioned as part of this policy. This includes part funding during a surrogacy cycle.

4. Eligibility criteria for accessing fertility services

4.1 Minimum and maximum age

Any treatment cycle will not be commenced before the female is 23 years of age but must be commenced before the female reaches her 40th birthday.

Any treatment cycle must be commenced before the male is 55 years of age.

4.2 East of England Resident

Couples must be resident within the east of England for 12 months prior to treatment. Active forces personnel are exempt from the 12 month east of England residency requirement.

4.3 Body Mass Index

The woman must have a body mass index of between at least 19 and up to and including 30 prior to referral for fertility treatment and at any time throughout treatment.

4.4 Maximum FSH Level

A maximum FSH level of 15U/L on day 2 of any menstrual cycle. Where couples are eligible for IUI treatment with donor eggs, the female must not have menstruated for 9 months.

4.5 Duration of sub-fertility

The criterion in this policy apply to couples who have an identified cause for their fertility problems or have infertility of at least three years duration.

4.6 Previous IVF treatment

Previous privately funded treatment will not preclude patients from being eligible to NHS funded cycles up to a maximum of 6 embryo transfers or 3 fresh cycles. However previous cycles, whether NHS or privately funded, will be taken into account by the responsible clinician in determining the clinical appropriateness of commencing further cycles. In line with current clinical evidence, couples should undergo no more than 5 fresh cycles in total.

4.7 Smoking status

Where couples smoke, only those who agree to take part in a supportive programme of smoking cessation will be accepted on the IVF treatment waiting list, and should be non-smoking at the time of treatment.

4.8 Parental status

There should be no living child from the couples current or any previous relationships, regardless of whether the child resides with them. This includes any adopted child within their current or previous relationships; this will apply to adoptions either in or out of the current or previous relationships.

4.9 Previous sterilisation

Couples are ineligible if previous sterilisation has taken place (either partner), even if it has been reversed.

4.10 Child welfare

Couples must conform to the statutory 'Welfare of the Child' requirements.

4.11 Medical conditions

Treatment may be denied on other medical grounds not explicitly covered in this document.

5 REFERRALS

5.1 Couples who experience problems with their fertility will attend their GP practice to discuss their concerns and options. The patients will be assessed within the Primary and Secondary Care setting.

5.2 A decision to refer a couple for IVF or other fertility services will be based on an assessment against the east of England eligibility Criteria which is based on the NICE guidelines and the HFEA recommendations as detailed in the clinical pathways.

5.3 Referral to the tertiary centre will be via a consultant gynaecologist or GP with Special Interest (GPSI) in primary care.

Bedfordshire Clinical Commissioning Group

Appendix 2

Specialist Fertility Consultation

Key Findings from the Formal Consultation

Sarah Frisby

Patient and Public Engagement Manager

November 2014

NHS – Add Protective Marking Category Here

better care, better value, better health

Contents

Appendices

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

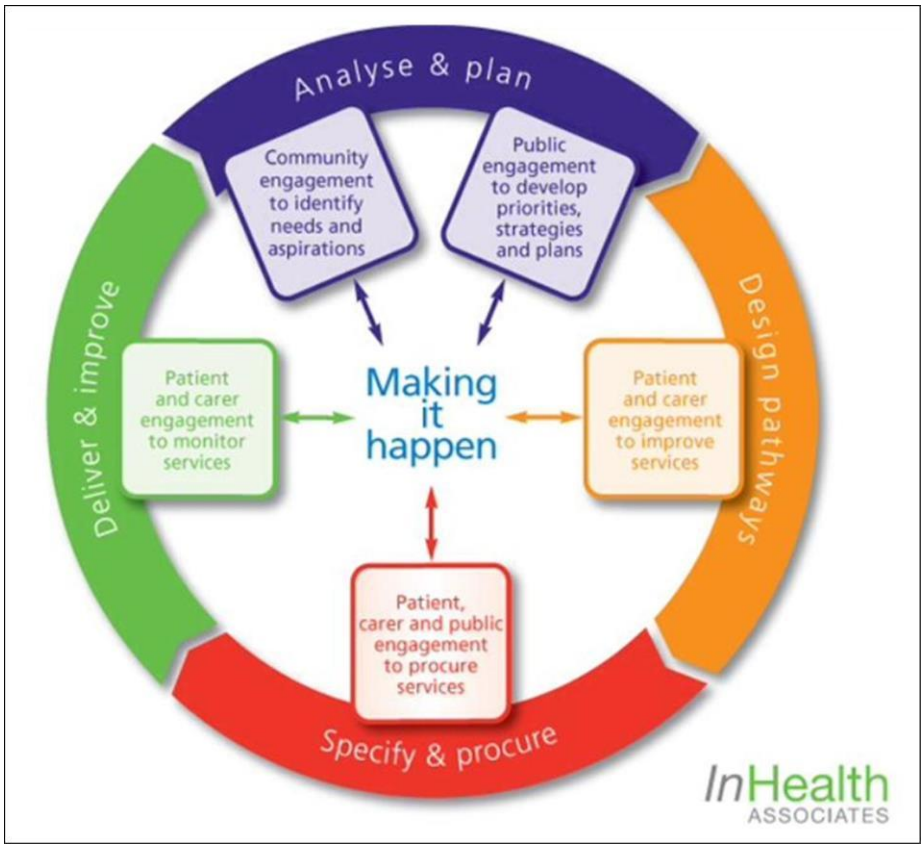
To establish who the key stakeholders were in this process, the project manager and the patient and public engagement manager, spent some time going through a stakeholder mapping exercise. This ensured that BCCG identified the stakeholders needed to involve in the engagement and consultation moving forward. 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 EoE 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 actively 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 ere 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 ensuing 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.

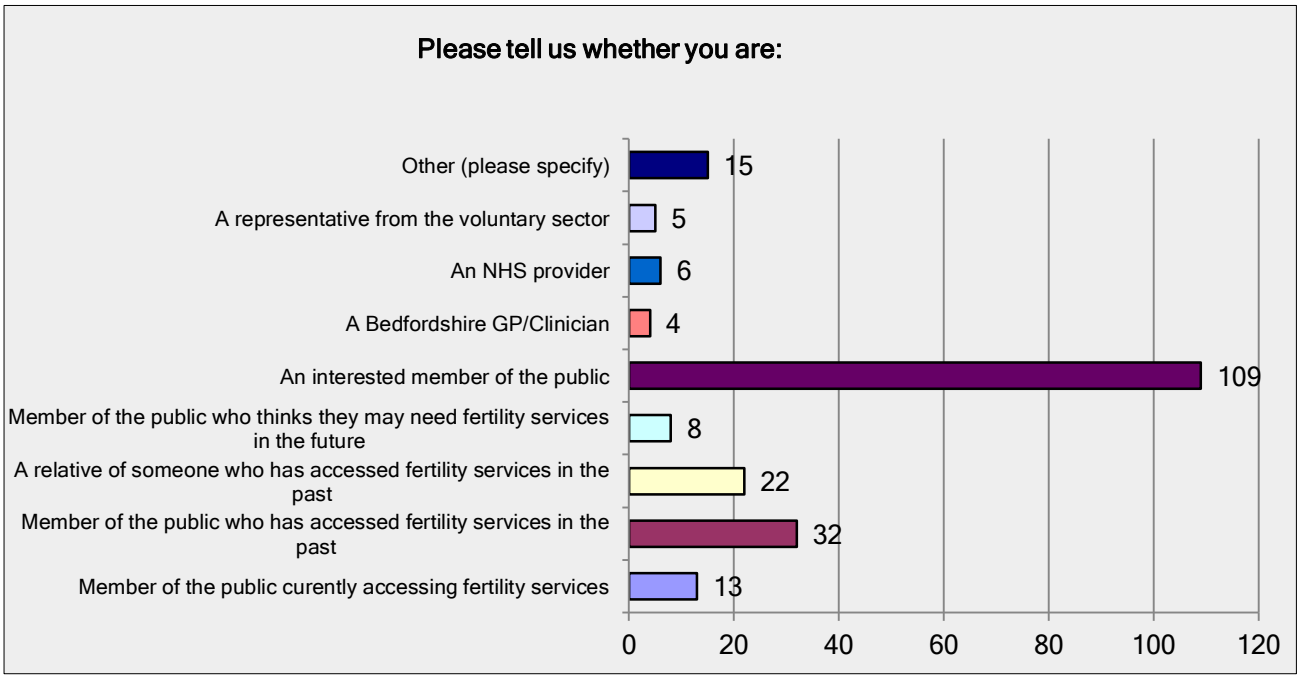
Stakeholder Feedback Analysis

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.

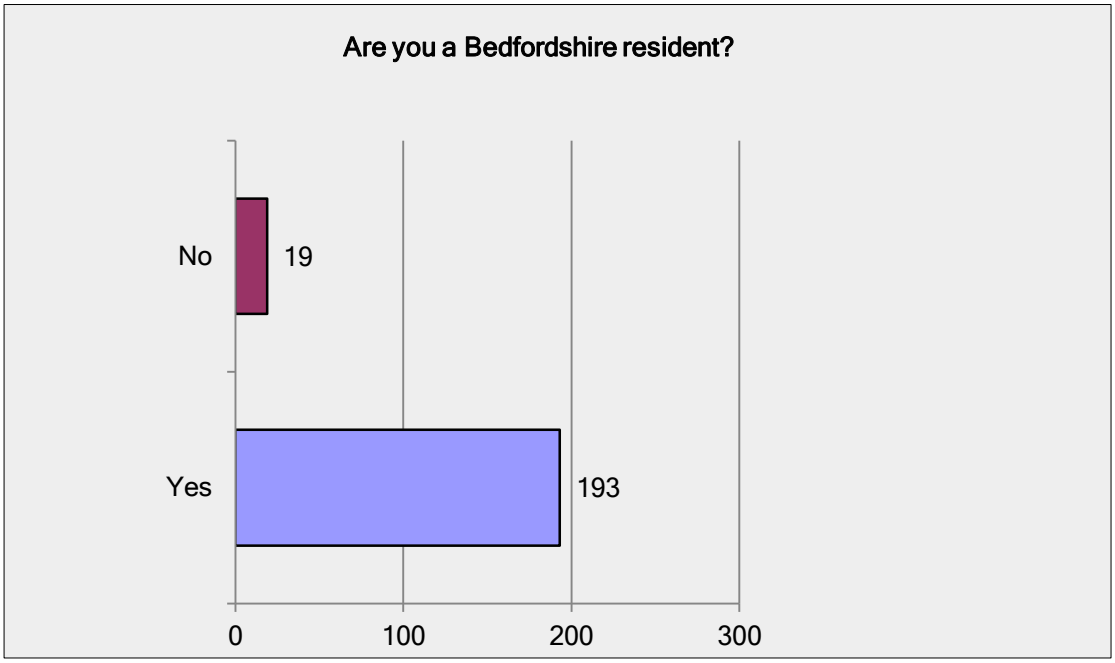
The breakdown of the responses are as follows:

Question 1:



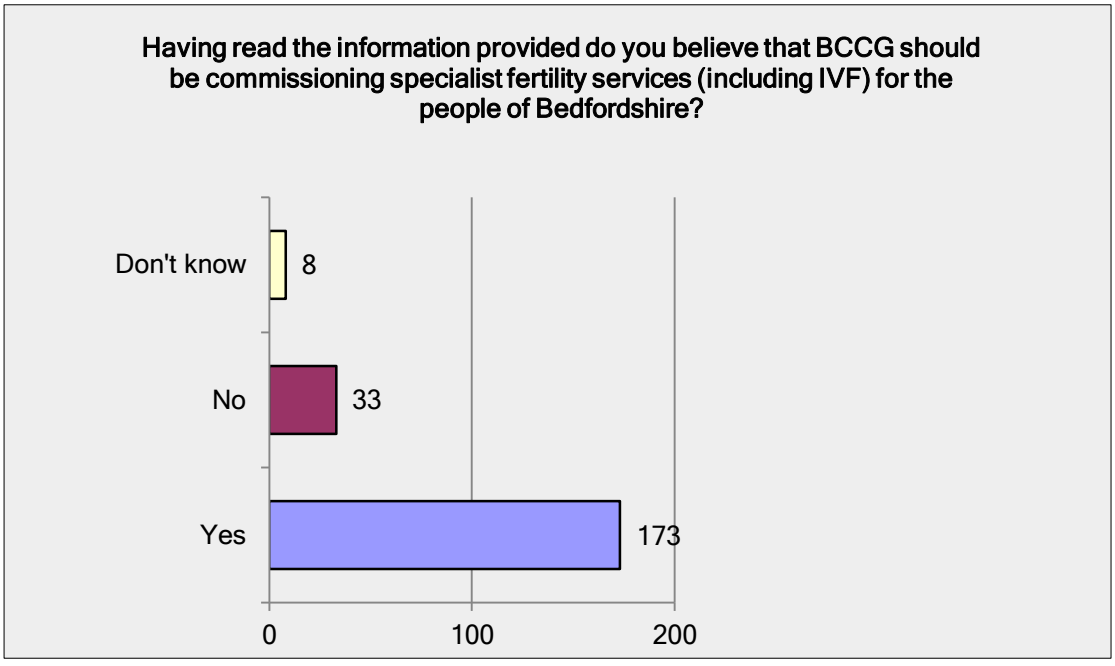
(1 skipped answer = 214 responses)

Question 2:



(3 skipped answers = 212 responses)

Question 3:



(1 skipped answer = 214 responses)

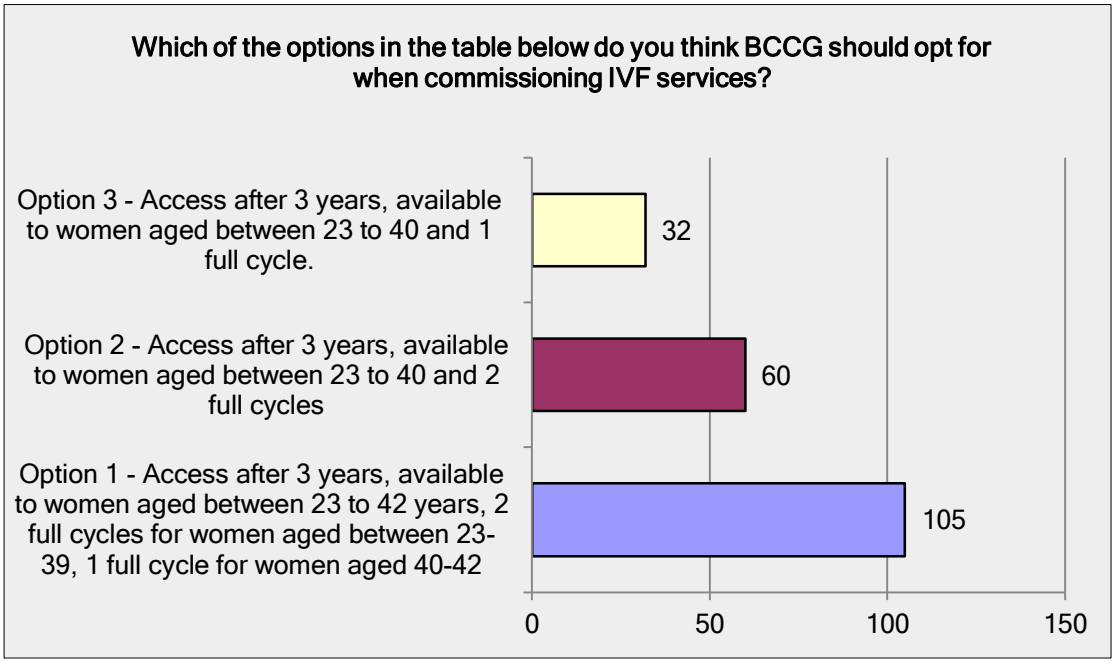
Question 4

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:

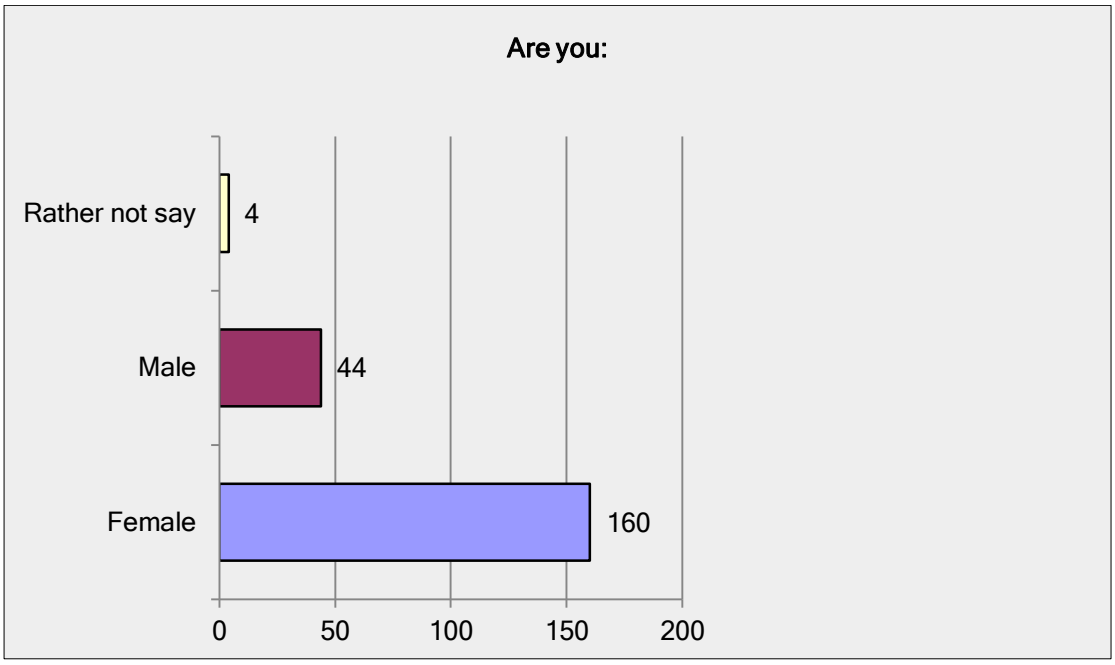
What do you feel is the most important consideration for BCCG when making decisions about the IVF eligibility criteria for the future? (1 high - 5 - low)							
Answer Options	**1**	**2**	**3**	**4**	**5**	**Rating Average**	**Response Count**
Age Range	58	52	43	21	12	2.34	186
Number of cycles	59	44	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)

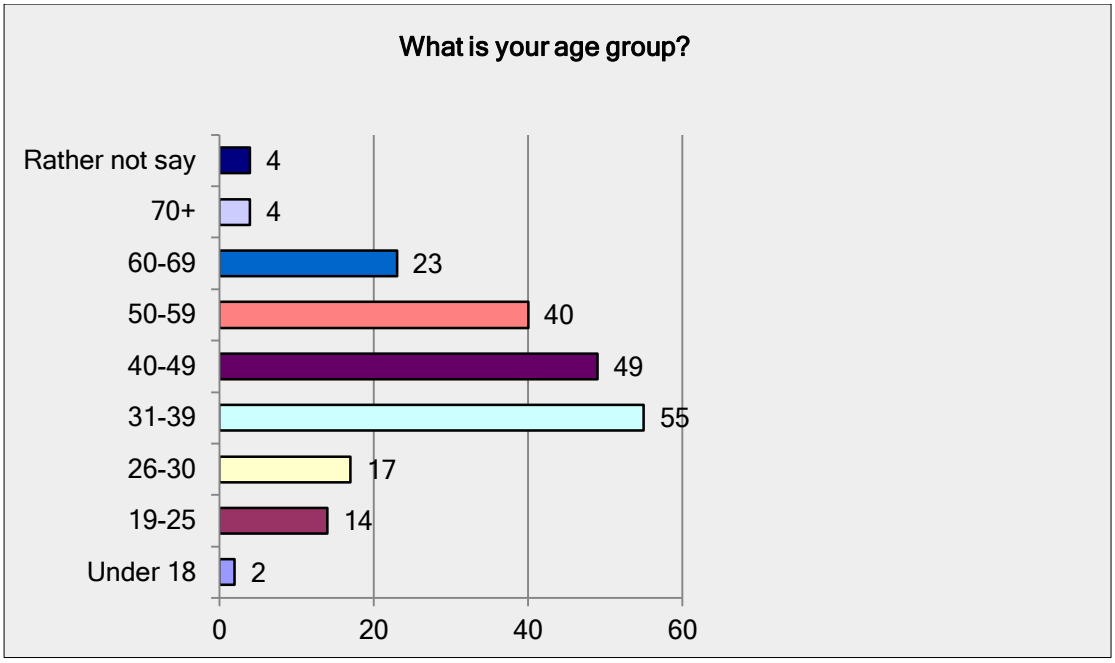
Question 7 asked respondents to make any other general comments on the consultation. Below is a cross section of responses:

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).

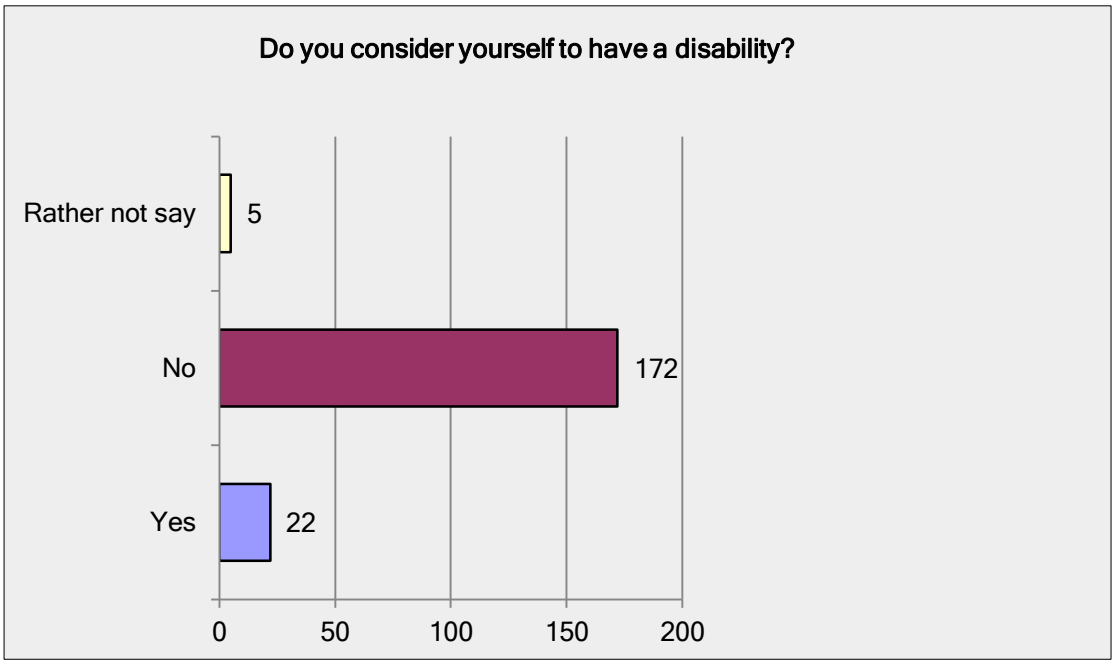
Demographic questions:



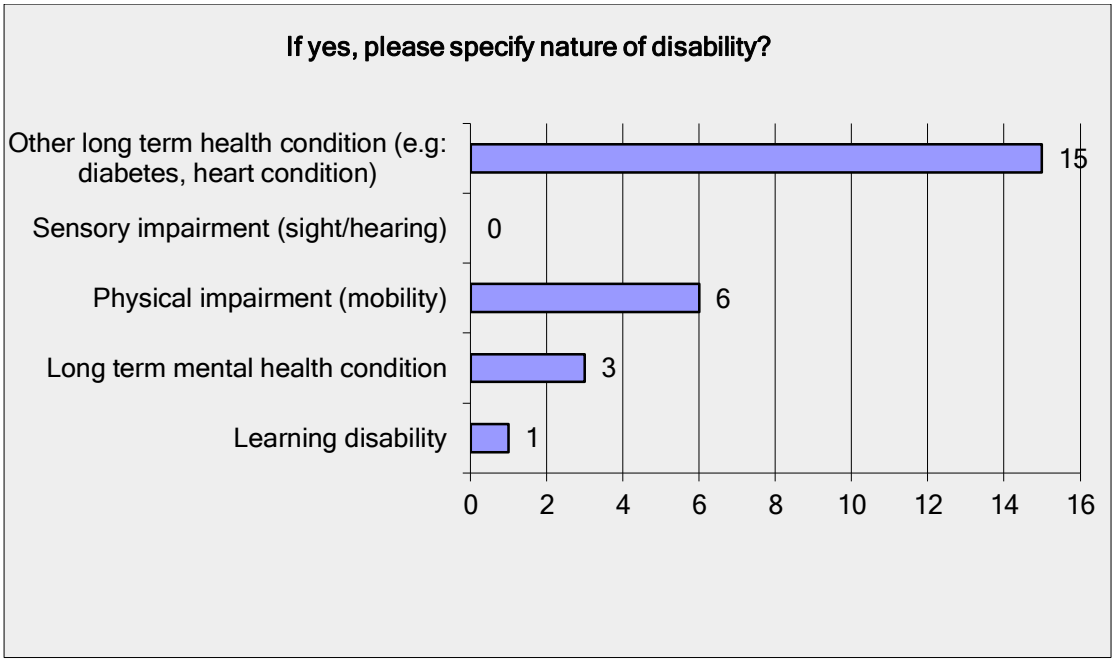
(7 skipped answers = 218 responses)



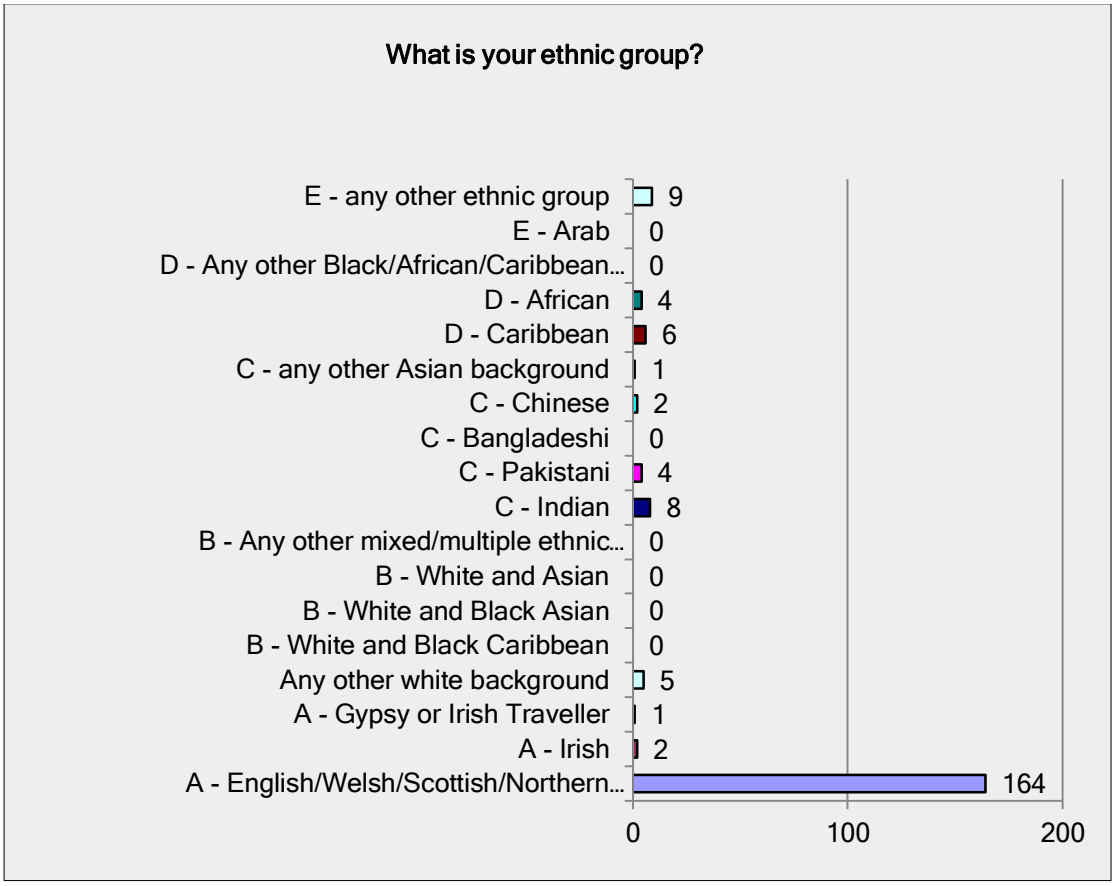
(7 skipped answers = 208 responses)



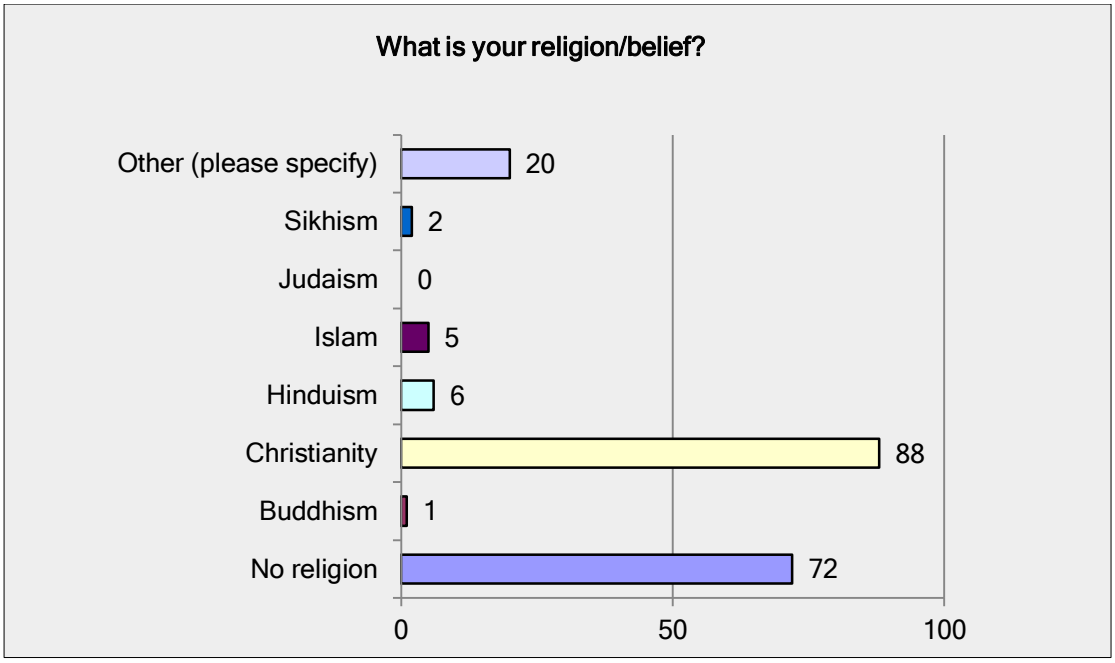
(16 skipped answers = 199 responses)



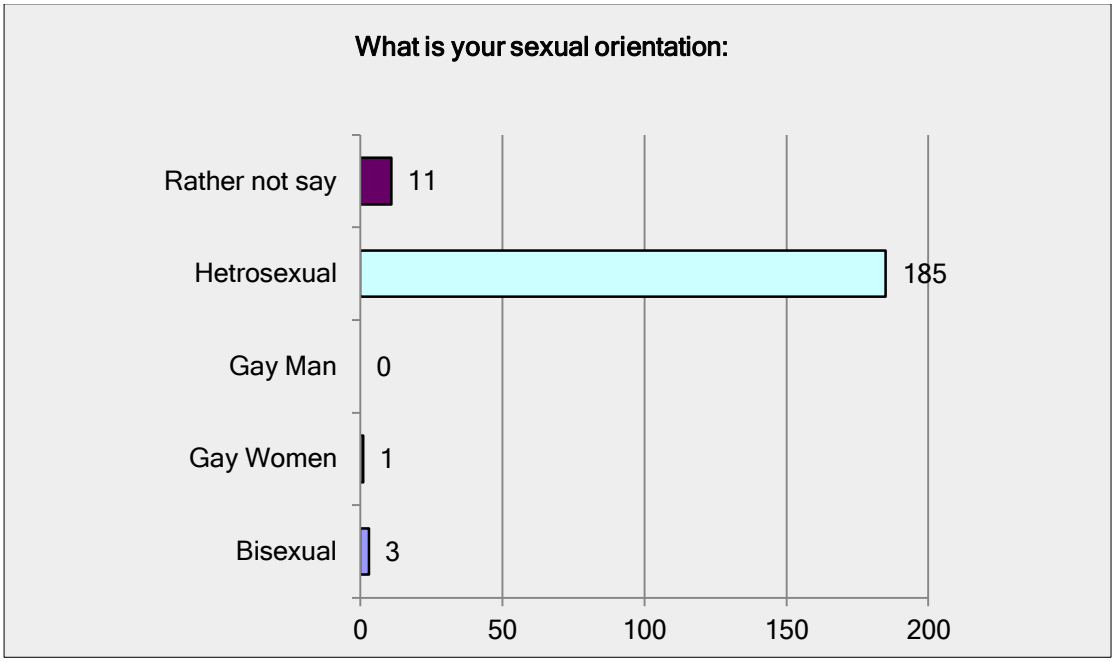
(24 responses)



(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.

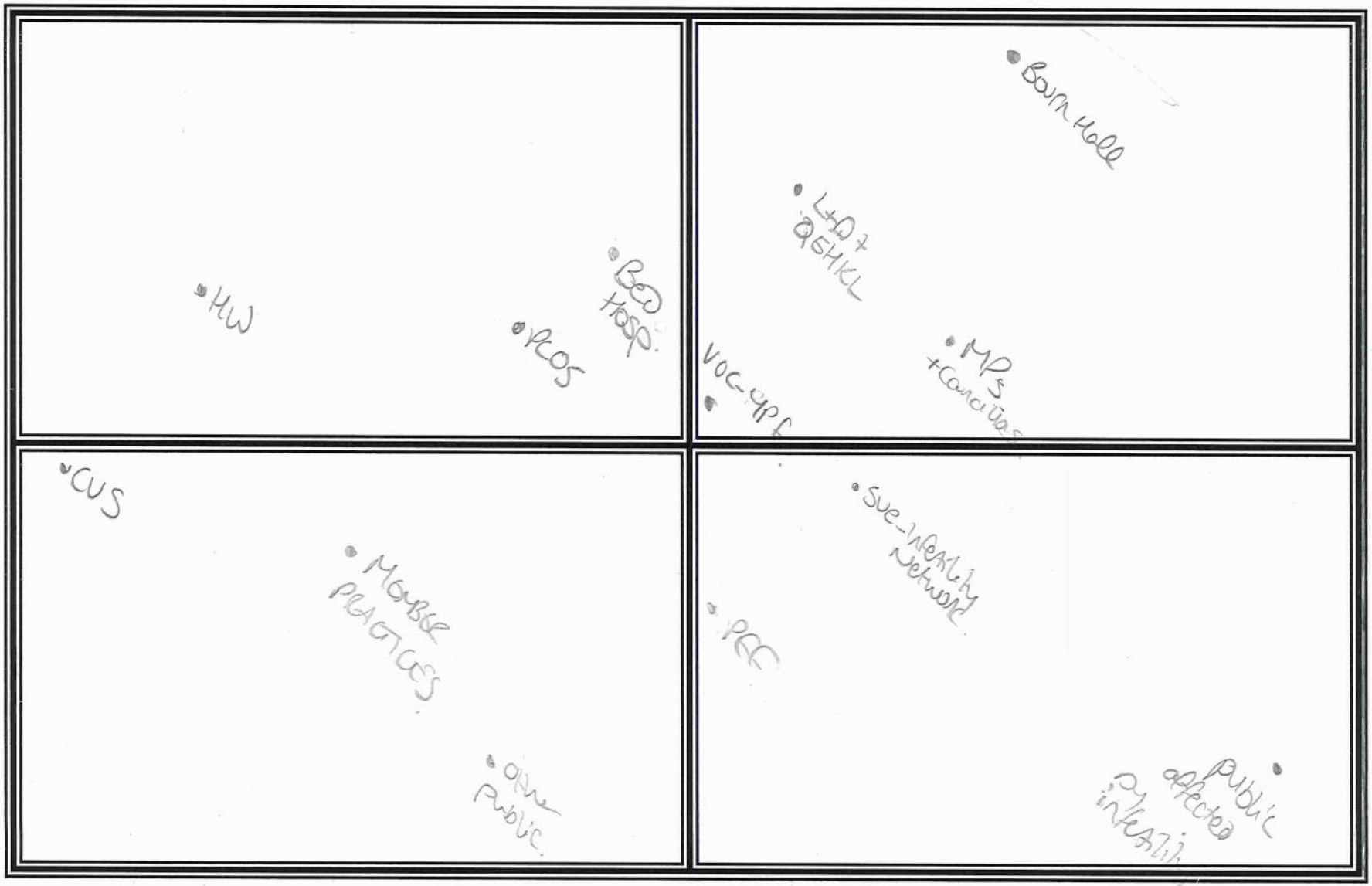
BCCG recognises the need for a meaningful and appropriate level of consultation in respect of IVF and has therefore been in discussion with the Consultation Institute (CI). BCCG has been successful in securing a dedicated resource from the CI who would work with BCCG in developing a sensitive but purposeful 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

consultation INSTITUTE
making consultation count

Stakeholder Mapping Matrix



LOW STAKE

INTEREST / COMMITMENT

HIGH STAKE

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 genecology 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 the 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	Ampthill 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 toWomens 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	Ampthill - 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 consultaton 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 consulation. 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!

BEDFORD BOROUGH COUNCIL

Borough Charter granted in 1166 *Chief Executive: Philip Simpkins*

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

NHS
Bedfordshire
Clinical Commissioning Group

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 in taken.

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

Yours sincerely

Dr Gail Newmarch
Interim Director of Strategy and Redesign

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Appendix

CENTRAL BEDFORDSHIRE COUNCIL

ADULT SOCIAL CARE
&
PUBLIC HEALTH SERVICES

CUSTOMER FEEDBACK –

COMPLAINTS
COMPLIMENTS

ANNUAL REPORT
2013/14

Document Status – Not Protected

INTRODUCTION

This report fulfills the statutory duty to monitor the effectiveness of the complaints procedure and produce an annual report for Adult Social Care and Public Health complaints. The report will be presented to the relevant local authority committee and will be made available on the Council's website.

The report provides statistics for 2013/14 on; the number of complaints received including those considered by the Local Government Ombudsman (LGO); the number of complaints that were well founded (upheld fully or in part); a summary of the complaints subject matter; performance; and the actions taken to improve services as a consequence of complaints.

In May 2014 the LGO released a report on Adult Social Care complaints for 2013. The key messages about effectiveness of a complaints procedure have been taken into account in this review (Section 5).

EXECUTIVE SUMMARY

The Adult Social Care and Public Health complaints procedures contain a number of different options to handle complaints. Individual complaints are assessed with the emphasis on understanding the complaint at the outset and taking the right approach to resolve it.

Each option for handling complaints has a minimum standard timescale for responding:

- Local resolution by Service Manager – 10 working days, 20 for complex cases
- Formal Investigation – 25 up to 65 working days
- Conciliation – 10 working days
- Mediation – 25 working days

However, timescales can be flexible depending on the nature of the complaint. An extension to a timescale is acceptable where this is negotiated and communicated to the complainant. When the Council has fully considered a complaint the next stage is referral to the Local Government Ombudsman.

<u>Adult Social Care</u>

There were 85 new complaints received in the period compared to 61 the previous year, the majority related to services for older people.

81 complaints were actioned and closed, and 80 of these were dealt with by Local Resolution. One case was investigated formally by an external investigator and resolved.

Complaints were seen as important feedback for services and a means of considering how to change things for the better. Services were receptive to customers' views and complaints, with 68% of complaints either upheld fully or in part. Whilst individual cases had specific remedies put in place, wider services improvements were also identified in a number of cases. These are detailed in Section 4.

There were also many instances of customers telling us that services were getting it right and having a positive impact on their lives. There were 65 compliments this year compared to 64 last year.

Public Health

The Public Health Service in Central Bedfordshire delivers the majority of its services by commissioning from external providers who are expected to manage their own complaints. However, the Stop Smoking Service is delivered directly to residents by Central Bedfordshire Public Health staff. There were no formal complaints registered for the service. There were 2 compliments registered about the helpfulness of the stop smoking service. This review has highlighted that not all customer feedback has been formally recorded.

Effectiveness

The activity for this reporting period shows the complaints procedure has been effective at resolving customer complaints at a local level. In Adult Social Care learning from customer experience through complaints has led to improvements to practices.

A plan has been put in place to improve the recording and handling of customer feedback for the Stop Smoking Service to improve the review of effectiveness of the procedure next year.

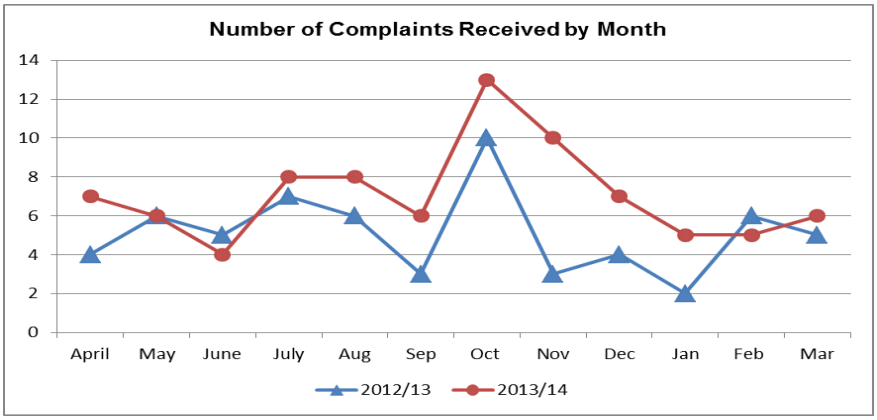
1 SUMMARY STATISTICS – ADULTS SOCIAL CARE

1.1 Headline Data for Customer Feedback

Feedback Received	Q1	Q2	Q3	Q4	Total
Complaints	17	22	30	16	**85**
Compliments	18	19	18	11	**66**

1.1.1 In 2013/14 there were 4484 records of adults receiving services funded by Adult Social Care Services. There were 85 new complaints received, last year 61 new complaints were recorded.

1.2 Spread of Complaints Received



1.2.1 In both years the peak month for complaints was October, followed by an overall downward trend until January. The peak of 13 complaints in October this year was largely due to two sources; six complaints about externally commissioned home care providers, and three complaints about errors in the Council's invoicing for care. The themes were not repeated in the following month. In the previous year there was no single cause for a peak in the complaints received in October.

1.3 Trends - Services Most Complained About

1.3.1 The service receiving the most complaints was the Older People Service, receiving 43 of the 85 complaint:

The majority of the 43 complaints related to social work management of cases (24). The main causes of dissatisfaction were; the assessment process; decisions and advice regarding funding; assessment and support for carers; poor communication and customer care.

There were 16 cases about services provided by external companies on behalf of social care; home care (10); residential (5) and meals services (1):

> For home care, 6 cases were about late or missed calls. Other concerns related to help with medication; the quality of care; communication; and use of equipment.

For residential care complaints related to quality of care; staff attitude; poor handling of support for hospital appointment; and poor attitude of staff.

1.3.2 A further 37 cases were spread over three additional service areas:

Learning Disability Service received 13 complaints mainly related to care management of cases (5) and residential care (4).

There were 13 complaints about Disability Services, mainly about home care services (5) direct payments (3), occupational therapy services (3).

There were 11 complaints about Financial Services mainly related to; invoicing issues (5) and direct payments (3).

1.3.3 Five remaining complaints related to the Safeguarding Service (4) and the Emergency Duty Service (1).

1.4 Outcomes from concluded Complaints

1.4.1 During the period 4 complaints were not suitable for the complaints procedure and dealt with using other procedures, and 4 cases were withdrawn.

81 Social Care complaints were actioned in the period. Complaints were seen by services as an important means of identifying areas for improvement. A total of 68% of complaints were deemed to be well founded in full or in part. Remedies were put in place for individual complainants. Section 4 details wider actions and improvements resulting from complaints.

1.5 Local Government Ombudsman (LGO) Complaints 2013/14

1.5.1 The Council received 3 complaint enquiries from the LGO related to Older People's Services in the reporting period.

In two cases the decision was not to investigate as the LGO was unlikely to reach a different outcome to that already identified by the Council. In the third case the LGO did not find fault.

The outcomes in these cases suggest the Council took appropriate action locally to remedy complaints.

1.6 Compliments

1.6.1 There were a significant number of customers who experienced good quality services that made a real difference to their lives such as alleviating the fear of isolation and feeling vulnerable; feeling a huge relief and weight lifted; a major change in their wellbeing. Compliments related to the quality, helfpulness and timeliness of services and support. Staff were praised for their helpfulness, compassion and professionalism. There were 65 compliments recorded across a range of services:

27	Older People's Services*	7	Contracts Services
10	Reablement Services	5	Disability Services*
7	Learning Disability Services	4	Finance Services
2	Home Care (External Provider)	2	Out of Hours Service
1	Safeguarding Team	2	Public Health – stop smoking

*including Occupational Therapy Services

1.6.2 The Older People Service received the most compliments. Whilst they had received complaints about poor communication and customer care there were also compliments from customers who experienced very good levels of communication and professionalism. Customer's appreciated workers being friendly; sensitive; and treating them with respect.

1.6.3 For other services customers took the time and trouble to say thank you for; finding the right care; respite; excellent customer service; a good quality review; ensuring carer's needs were met; great quality reablement services.

The Contracts Team received compliments from external providers for the support and guidance given to them to improve their own services to customers.

2 EQUALITY & DIVERSITY MONITORING

2.1 The purpose of capturing equalities data is to monitor access to the complaints procedure; to ensure services are appropriate for all service user groups; and to check whether any issues relating to discrimination have been raised. Data relates to the service user affected by the complaint or a person who has been affected by the actions taken by the service. The system used for Adult Social Care complaints has the facility to capture the service user's gender, ethnicity and whether the service user describes themselves as having a disability or not. However, the system has limited reporting functionality for analysis in this area to meet the needs of equality and diversity monitoring. Therefore, we can't easily analyse the detail of complaints and trends relating to discrimination/human rights/age.

2.2 In 2013/14 there were 4484 records of adults receiving services funded by Adult Social Care Services. There were 85 new complaints received

2.3 Accessibility to Complaints

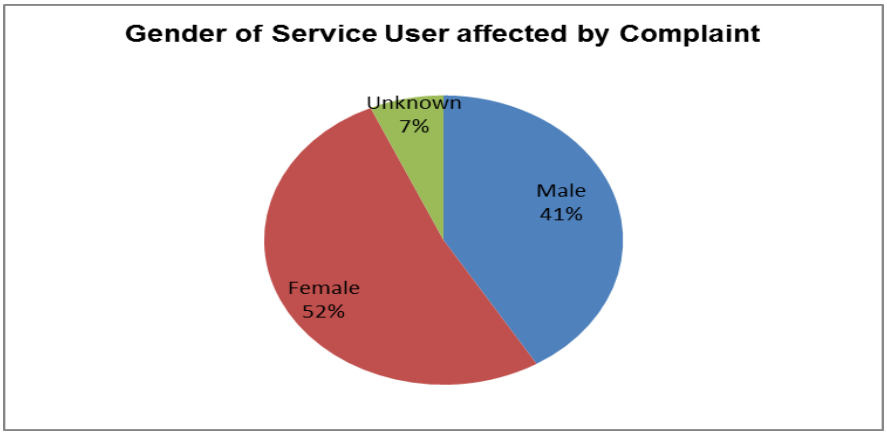
By having a range of contact options for complainants to make their complaints the Council aims to meet the needs of its service users in accessing the complaints procedure. People can make complaints in person; face to face or via telephone (including a direct line to Customer Relations), in writing; via email, letter, or complaint form.

2.3.1 <u>Receipt Method for Complaints</u>

79% of complainants preferred to make their complaints in writing; via email; or letters or complaint form. 18 % made complaints by telephone. The remainder preferred to make a complaint in person.

58% of complaints were made by representatives of service users, the majority of these were made by relatives or partners of the service user, showing that people affected by the actions of Adult Social Care accessed the complaints procedure.

2.4 Social Care Complaints – Gender



2.4.1 Where information was captured 52% of complaints affected female service users, 41% affected males. Allowing for the 'unknowns' this broadly reflects similar proportions of service users receiving services where 61% were described as female and 39% male. Service users of both genders are represented in the complaints procedure and both genders were affected by similar issues. However, males were more affected by complaints about financial administration matters than females, with 7 identified as male and 1 as female. Issues related to invoicing errors (which affected both genders) and; financial assessment; closing a direct payment; handling of personal information.

2.5 Social Care Complaints – Race

2.5.1 93% of service users receiving services were described as White British. A high proportion of complaints (85%) were recorded with 'unknown' race which may mask representations from ethnic backgrounds not reflected here. 13% of complainants were recorded as 'White UK'. White Other' (2%) was also represented in complaints. The issues for complainants described as 'White Other' were similar to those raised by complainants recorded as 'White British'.

2.6 Social Care Complaints – Disability

2.6.1 In 22 % of complaints service users described themselves as having a disability. However, a significant proportion of cases were recorded as 'unknown'. Social care services include services for older people, disabilities and adults with learning disabilities. Therefore, it is anticipated that a significant proportion of complainants would describe themselves as having a disability. The figures demonstrate that people with disabilities are able to access the complaints procedure.

2.6.2 The 13 complaints identified as affecting people accessing the physical disabilities services were about the quality of service relating to direct payments, occupational therapy assessments of need; home care; and review of needs.

2.6.3 For those with a learning disability concerns were mainly about the assessment or review of their needs (5 complaints) and the care provided in residential settings (4 complaints).

3 PERFORMANCE

3.1 There is no timescale in Regulations in which to resolve complaints. The emphasis is on assessing the complaint at the outset to fully understand the issues, and then planning a clear method of handling the complaint in a reasonable timescale. Timescales can be re-negotiated with the complainant if appropriate. Managers are encouraged to set out an action plan for the complaint detailing how it will be dealt with.

3.2 There were 81 complaints concluded, 80 were dealt with using the local resolution method; and one case was concluded following a formal investigation by an external investigator. Action plans were in place for 70% of cases, setting out how the complaint would be handled; 77% of these were completed in line with the timescale in the action plan.

4 SERVICE IMPROVEMENTS FROM COMPLAINTS

4.1 Learning and Improvements from Complaints Received
Remedies were put in place for individual complainants, for example an apology; review of service; providing information; an assessment. However, managers also looked to see if there was any need to improve services by make changes to practices or procedures. The wider learning actions are set out below.

4.2 Learning & Improvements from Complaints about Externally Provided Care Services (Commissioned Services)

4.2.1 Poor care in the home or in a residential setting, can have a significant impact on service users. The majority of these services are provided by external companies paid for in full, or in part, by Adults Social Care. Managers ensured complaints about externally provided services were responded to fully and that appropriate action was taken to remedy mistakes.

As part of their wider work to monitor commissioned services, the Contracts Team proactively seek to understand service user experience of the care provided. They carry out service user surveys both annually for residential care, and case by case for those receiving home care. In addition they also receive information on complaints and take appropriate steps to manage any wider contractual concerns. Where appropriate the Contracts Team worked with care providers to put in place action plans to improve.

4.2.2 Actions taken by external companies to improve their services included; additional training and support for staff; improving the approach to communication with customers; and putting in clear processes or policies. Examples of action taken as a direct result of complaints are set out below:

- moving and handling training is a mandatory requirement and full training to be provided in the use of all equipment including the use of slings;

- workers to undertake further training in communication and customer service skills as well as dignity and respect training;

- introduction of a communication book for medication issues;

- the provider will firmly instil a policy of hygienic practice throughout the company and all carers will receive further training to ensure that appropriate standards are maintained;

- plan put in place to increase staff levels and ensure improved rotas and consistency of staffing;

- staff undertake a more detailed course called 'Person First Dementia Second'

4.3 Learning & Improvements from Complaints about Social Work Practice

4.3.1 Service users and their families value timely, relevant services and clear communication and information from social workers. Complaints led to the following actions to improve:

- Staff within SEPT and Adult Social Care were reminded of the importance of effective communication with family members during the safeguarding process. SEPT gave assurances that in the future a strategy planning meeting will be held as soon as practical and be seen as highest priority to ensure that there is effective joint working between the different agencies.

4.3.2 <u>Older Peoples Services</u>:

a) Further training on the carer's criteria. Carrying staff vacancies had been a contributing factor in a complaint and the service employed further locum staff and was actively recruiting.

b) Following a failure to explain the financial implications of residential care, social workers were reminded of the importance of providing relevant information. The manager will carry out spot checks to ensure this has happened and is recorded. In addition, the Home Finder Team was asked to also send out a booklet to all families they are in contact with.

c) To address delays due to staff absence, team managers are required to ensure work is either reallocated or covered for short periods through the Duty process.

d) A carer felt unsupported during safeguarding interventions. In the future, where required, the service will allocate carers a social worker at the onset to support them through a safeguarding investigation.

e) Following a complaint about lack of information on the authority's process for Continuing Health Care, staff were advised to provide documented evidence that appropriate financial information has been given. Workers now confirm in case records that financial advice has been given, before agreement for a placement is made.

4.3.3 <u>Occupational Therapy Service:</u>

A complaint highlighted delay for a customer requiring an urgent assessment. To ensure cases are prioritised correctly the Manager contacted colleagues within the contact centre and requested that they check when receiving a referral whether the equipment is needed

to assist a hospital discharge. Referrals are scanned on a daily basis to ensure any referrals involving hospital discharge are picked up.

Following a complaint about lack of response to messages the manager monitors caseloads and strategies to ensure officers can provide timely responses to customer's communications.

The quality of referrals and communication will be reviewed at the end of August to consider further improvements

4.3.4 Learning Disabilities Service

Delay providing a carer's assessment was in part as a result of a case being misdirected internally to children's services. The manger committed to recommending to colleagues in Children's Services that they provide a clear pathway to the customer contact centre in order help reduce the risk of misdirection.

4.3.5 Physical Disabilities Services

A formal investigation into a complaint about the lack of care and engagement found problems with the general approach to assessing and supporting parent's social care needs; including how the Council could facilitate support for parents in their caring role. As a result, support planners were transferred to locality assessment teams as part of a workforce review so their work is overseen by social workers. In addition the service also expanded their safeguarding team to incorporate the role of quality assurance to include auditing support planners work.

Following the work to follow up on the learning from the complaint managers reported they were clear in their assessment responsibilities to support disabled people in their parenting role

5 EFFECTIVENESS OF COMPLAINTS HANDLING

5.1 Response to a Recent LGO Report on ASC Complaints 2013

In May 2014 the Local Government Ombudsman (LGO) published a review of Adult Social Care complaints for 2013. It suggested Local Authorities should review the data on complaints to consider the quality of care and effectiveness of complaint handling in their area. The report related to complaints in 2013 and can be found on the LGO's website:

http://www.lgo.org.uk/publications/annual-reviews/

The report raised the question whether councils with low dissatisfaction but high numbers of complaints to the Ombudsman meant users of services had to escalate their concerns to the LGO due to inadequate complaints resolution at the local level. It also suggested that where complaints were upheld by the LGO this could be as a result of failures in the Local Authority's local handling of complaints.

The data in the report relating to Central Bedfordshire Adults Social Care in 2013 set out that the LGO upheld two complaints. In both cases the LGO did

not instigate an investigation and was satisfied with the actions taken by the Local Authority through its own complaints procedure to resolve upheld complaints.

The decision on a further two cases was 'not upheld'. So whilst the LGO agreed with the Council that two complaints were upheld, it is clear that the service had taken the right approach when dealing with complaints. This gives confidence that the service has a focus on resolution and remedy. It does not suggest escalation to the LGO is due to inadequate complaints resolution at the local level.

5.2 Future Plans on the Approach to Improving & Learning from Complaints

The customer relations manager attended the social care manager's meeting to discuss complaints handling and performance. Operational Managers will engage in quarterly reviews of complaints handling and will be sited on quarterly reports and contribute where relevant. A key focus of complaints is learning and ensuring practice issues have been embedded. The Adult Social Care Service plans to put in place a Practice Governance Board and Forum and learning from complaints will be included in this work

There is room for improvement to ensure all complaints have an individual action plan and that complainants are kept informed of progress. The senior management team will be promoting this action through their respective Management Teams and the staff newsletter. Performance will be monitored through the Performance Board.

The Public Health Service delivers a Stop Smoking Service directly to residents. The remainder of the Council's Public Health Services are delivered through contracts with service providers who are expected to manage their own customer feedback including complaints. Service provider's contracts are monitored. Plans are in place to improve the recording and handling of customer feedback for the Stop Smoking Service that should improve our ability to review the effectiveness of the feedback procedure next year.

5.3 Summary of Effectiveness

The information for the reporting period shows that service users; their representatives; and people affected by the actions of Adult Social Care access the complaints procedure.

Local Resolution has been an effective means of dealing with complaints with 99% of complaints resolved through local resolution by managers of the service complained about.

With 68% of complaints deemed to be well founded in full or in part complaints were seen as a valuable source of information about customer experience and an opportunity to remedy mistakes. Managers took action to improve practices.

Where they were involved, the LGO agreed with the actions taken by the Council through its own complaints procedure or found no fault. The complaints procedure is effective and demonstrates that when complaints highlight mistakes the services are receptive to customer feedback and to putting things right.

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