Appendix 1

Policy Alignment Consultation 2021 - Case for Change - Pre-Engagement Comment Tracker

Date	Organisation / Role	Current wording / content	Comments Received	Page No. / Location in document	Change Made (Yes/No)	If Yes - Changed to	If No - Reason	Notes
17/08/2021	Quality & System Performance NHS South, Central and West	Egg Donation - Current policies allow for egg donation under specific criteria.	Assume means the use of donor eggs, this and the use of donor sperm could be in one section perhaps	Appendix A - Table 1	Yes	Donor eggs and donor sperm - Current policies cover use of donors eggs and donor sperm under specific criteria.		
		BLMK CCG is proposing to implement the number of cycles as per the outcome of this consultation. BLMK CCG is proposing to apply NICE guidelines in relation to age criteria for service users (e.g.: patients up to the age of 42 will be eligible)	Is the current BCCG and LCCG minimum age criteria 23 years to be removed? This would be in line with NICE CG. Beneficial point in view of improving access conversations.	Appendix A - Table 2	Yes	BLMK CCG is proposing to implement the number of cycles as per the outcome of this consultation. BLMK CCG is proposing to apply NICE guidelines in relation to age criteria for service users (e.g.: patients up to the age of 42 will be eligible and the existing minimum age of 23 years stated in the existing BCCG and LCCG policies should be removed)		
		Donor Insemination	Assume this is just a section to refer to the use of donor sperm and donor oocytes as in the previous section i.e. funded. 'Donor insemination' may be confusing terminology it just is AI using donor perm, sorry may be a bit pedantic here…	Appendix A - Table 2	Yes	This row in the table has been removed on the rationale that it could be confusing and other sections clarify the use of donor eggs/sperm and IUI/AI. Also could be confusing to say not proposing to change because some aspects of access to IUI are expected to change.		
		Donor Insemination - BLMK CCG is not proposing to change this element of the policies but will add clarity by aligning the wording to NICE guidelines .	Agree that there needs to be a clear section on the requirements what is expected of same sex couples and women not in a partnership and people who are unable to, or would find it difficult, to have vaginal intercourse to establish their fertility status before seeking NHS funded services. This is discussed later in the page 10 section.	Appendix A - Table 2	Yes	as above this row of the table has been removed.		
		Minimum / Maximum BMI - BLMK CCG are proposing that BMI should be between at least 19 and up to 30 for female and less than 35 for male .	NICE CG notes that: 'Men who have a BMI of 30 or over should be informed that they are likely to have reduced fertility'.	Appendix A - Table 3	No			
		Duration of sub-fertility - Couples with unexplained infertility or mild male factor infertility/subfertility must have infertility of at least 3 years of ovulatory cycles, despite regular unprotected vaginal sexual intercourse.	Clinical evidence from NICE notes that 84% of women would conceive within one year of regular unprotected sexual intercourse, 92% after two years and only a one per cent increase to 93% after three years. NICE made this change in 2013 from 3 to 2 years due to the small increase as noted above. This could be a positive point for improving access to services conversation, coupled with the fact that that female fertility declines with age and therefore waiting longer for referral for specialist services potentially drives down success rates. Reducing the time period of expectant management from three years to two years in instances of unexplained infertility would impact on cost and activity in the first year of implementation, before a 'steady state' is achieved.	Appendix A - Table 3	Yes	Following discussion at the 'clinical panel' on Wed 15th Sept agreed to change the duration of sub-fertility from 3 years to 2 years based on the clinical evidence from NICE.		
		IUI (Unstimulated)	Just for clarity maybe it would be good to discuss this under a title of for 'patients who have who have social, cultural or religious objections to IVF - the use of 'replacement cycle' would avoid confusion with the other AI discussion. Have we reviewed the equivalence of the one IUI to one IVF. I believe LCCG policy states 6 IUI as replacement cycles for one IVF if I have the right 2019 version.	Appendix A - Table 3	Yes	Patients who have who have social, cultural or religious objections to IVF - BLMK CCG is proposing to implement the number of IUI cycles in line with the number of IVF cycles agreed as per the outcome of this consultation. e.g. 1 cycle of IVF offered = 1 3 cycles of IUI offered. 3 cycles of IVF offered = 3 9 cycles of IUI offered. This would still be applicable under exceptional circumstances and an IFR/ITP application for funding has been made.		
		Same Sex Couples	Think this section should include; women in same-sex couples, single women and couples not able to have vaginal intercourse	Appendix A - Table 3	Yes	Women in same-sex couples, single women and couples not able to have vaginal intercourse		
		Same sex couples - female: Same sex female couples are entitled to 6 cycles of NHS funded donor AI or IUI.	Important to be specific that it should be IUI (not just AI as that can be both intra uterine or intra cervical) This section needs to clarify what is expected in terms of establishing fertility status before seeking NHS funding. LCCG position is referring to this i.e self-funded AI. For women in same-sex / or not in relationships or unable to have intercourse, there should be some period of unsuccessful AI before they would be considered to be at risk of having an underlying problem and be eligible to be referred for assessment and possible treatment in the NHS. NICE notes that: 'In women aged under 40 years who have not conceived after 2 years of regular unprotected intercourse or 12 cycles of artificial insemination (where 6 or more are by intrauterine insemination), offer 3 full cycles of IVF… 'For women under 40 who are using artificial insemination rather than sexual intercourse to conceive, more than half of women will get pregnant within 6 cycles of intrauterine insemination. Within 12 cycles, more than 3 out of 4 women will become pregnant'.	Appendix A - Table 3	Yes	Same sex couples - female: Same sex female couples are entitled to 6 cycles of NHS funded donor IUI.		
		Same sex couples - male: Same sex male couples will not be able to access fertility treatment within their relationship but will be eligible for appropriate investigation where there is evidence of subfertility.	Agree, the scope of NICE guideline makes it clear that it is intended for people who have a possible pathological problem (physical or psychological) to explain their infertility. However, if we promise to investigate, we would need to define when and that would need to be that same as for same sex female couples etc. If we are clear as per earlier point that that surrogacy is not funded by the CCG but all individuals can have access to sub fertility investigations as necessary not sure we need to make the point again for male same sex couples. The surrogacy point also covers other trans couples where the is not womb.		Yes	Section removed as surrogacy sections already covers these points.		
		Option 2b Trans or non-binary couples or individuals who meet all criteria in this policy must have had unexplained fertility for a period of 3 years. Or have received 6 cycles NHS funded donor AI or IUI. Or have a diagnosed cause of absolute infertility to be eligible to receive NHS funded fertility treatment.	If we discuss the patient groups in terms of couples trying to conceive and concerned about sub fertility i.e. couples unable to have intercourse, same sex couples, single women and trans or non-binary couples I think we have identified what the policy addresses and if we introduce the definition early in the policy, we do not need to single them out. What is expected in terms of 'evidence' for sub fertility and what is offered should be consistent for all. Thus not sure all these options are necessary and again using the exceptions process would single out different process for different patient groups.		Yes	Women in same-sex couples, single women and couples not able to have vaginal intercourse are entitled to NHS funded IVF treatment on the NHS following 6 cycles of NHS funded donor AI or IUI. BMI eligibility criteria above apply only to the female partner undergoing fertility treatment. The partner of a prospective person who has undertaken NHS funded fertility treatment, whether successful or not, will be deemed to have received their entitlement to NHS funded fertility treatment upon completion their treatment, in line with the criteria for heterosexual couples and will not be eligible for additional cycles with their partner or any future partners. Couples will be required to fit all other criteria within a policy in line with heterosexual couples.		
31-Aug-21	Pateint and Public Engagement Committee		How many pateints are affected by the policies in each area - make this clear in the Case for Change Document		Yes	Gluten Free numbers - see page 4 MK Pharmacy First Data - see page 5 During 2019/2020 480 people across Bedfordshire, Luton and Milton Keynes accessed IVF treatment, this is approximately 0.05% of the BLMK population.		Gluten free data already included (100 patients) JB added table to Pharmacy first which shows usage data
03-Sep-21	Fertility Network UK		What definition of a cycle is going to be used as currently all 3 CCG's are using different definitions and only MK use the NICE definition of a cycle?		Yes	The definition of a cycle and abandond cycle have been added to the glossary in the appendix detailing the criteria changes.		
03-Sep-21	Fertility Network UK	BLMK CCG has finite resources to fund a whole range of health services and treatments. Specialist fertility services are expensive treatments which can often prove unsuccessful. There is a real need to balance funding for this treatment with all other treatments/services across the NHS in Bedfordshire, Luton and Milton Keynes.	What modelling of data and costs have been used, it says it is expensive, but where does that come from – need to include rationale.	2	Yes	There is a real need to balance funding for this treatment with all other treatments and services across the NHS in Bedfordshire, Luton and Milton Keynes. The CCG's current annual spend on fertility services is £895,264 with an average cost per patient of £1,865. During 2019/2020, 480 people across BLMK accessed IVF treatment, this is approximately 0.05% of the BLMK population.		
03-Sep-21	Fertility Network UK		Need to look at how many people would move onto the second and how many would go onto a third and be eligible. What work has been done in this area to arrive at the options in the consultation?		No		As per above the modelling has been reviewed and assumptions about number of people who move onto second and third cycles is based on historical local data. The case for change explains the clinical discussion about criteria and how the criteria should look moving forward.	
03-Sep-21	Fertility Network UK	The Luton policy of routinely offering up to three cycles is at odds with the majority of the surrounding CCG Areas. Within the East of England health region, only Thurrock and the former Luton CCG offer more than one cycle. All others offer one, except for Cambridgeshire and Peterborough who do not currently fund any cycles (though they have recently proposed implementing a single cycle). In the wider geography, Oxfordshire, Buckinghamshire and Berkshire CCGs all offer only one cycle.	Cambridgeshire and Peterborough – check language used to explain their decision to re-instate (1 fresh and 1 frozen – not full cycle as per NICE)	2	Yes	The Luton policy of routinely offering up to three cycles is at odds with the majority of the surrounding CCG Areas. Within the East of England health region, only Thurrock and the former Luton CCG offer more than one cycle. All others offer one cycle and in the wider geography, Oxfordshire, Buckinghamshire and Berkshire CCGs all offer one cycle.		
03-Sep-21	Fertility Network UK		Projections – Figures in the document suggest that there would be an almost doubling in spending which is at odds with the Camden findings which show that very few people move onto to a third cycle. Also don't understand how the two options were reached – would be beneficial to think more holistically about what might be the right thing to do. Need to show rationale for the options.		No		We have used data collected through our Luton service, which is closer to demography than using the Camden data or national data.	
06-Sep-21	Healthwatch		The consultation documents need to show the detail behind the suggested changes in policy so that the public can have a full understanding of the changes and what they would cost.		Yes	Detail added including numbers accessing services and costs for each option		

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06-Sep-21	Healthwatch Luton	What is the cost of fertility services to BLMK CCG? The CCG's current annual spend on fertility services is £895,264. If the number of cycles was increased to 3 across BLMK this would increase to at least £1,670,149, an increase of £774,845. As the CCG has a finite financial resource, this would require consideration of where resources could be saved in other service areas. This may mean we would have to stop some other services so the money was available for this.	The language around having to reduce other services if these services are all levelled up can be seen as a threat to services	Pg 3	Yes	What is the cost of fertility services to BLMK CCG? The CCG's current annual spend on fertility services is £895,264. If the number of cycles was increased to 3 across BLMK this would increase to at least £1,670,149, an increase of £774,845. As the CCG has a finite financial resource, this would require a review of budget allocation.		
06-Sep-21	Healthwatch Luton	A decision was taken over 30 years ago to include gluten-free foods on prescription, when there was limited availability of gluten-free foods to buy. Today the availability of gluten-free foods has increased dramatically and they are found in almost all major supermarkets.	Documents state that there is an 'Abundance' of gluten free foods available, the language of abundance is not quite right.	Pg 3	Yes	A decision was taken over 30 years ago to include gluten-free foods on prescription, when there was limited availability of gluten-free foods to buy. Today the availability of gluten-free foods has significantly increased and they are found in almost all major supermarkets.		
06-Sep-21	Healthwatch Milton Keynes	Individual Funding Request (IFR) Process For all of the above proposals it should be noted that the Individual Funding Request (IFR) process is still available for patients who believe that they have exceptional circumstances. Any application needs to be made on behalf of the patient by a clinician, and the key point to remember is the need to demonstrate the exceptionality of the case – i.e. why the patient should receive treatment which is outside BLMK CCG's current funding arrangements. Further information can be found on BLMK CCG's website: https://www.blmkccg.nhs.uk/your-health/individual-funding/	IFR – Need to review the wording regarding IFR to make it clear that this is a challenging process and is only successful in specific circumstances	Pg 5	Yes	For all of the above proposals it should be noted that the Individual Funding Request (IFR) process is still available for patients. Funding requests are reviewed and decided upon by a panel but applications will only be taken forward if there are exceptional clinical circumstances. IFR applications need to be made on behalf of the patient by a clinician. Further information can be found on BLMK CCG's website: https://www.blmkccg.nhs.uk/your-health/individual-funding/		
06-Sep-21	Healthwatch		Preferred options – Need more rationale to show why they are the preferred options		Yes	Have included a paragraph ahead of each preferred option with outline of rationale.		
06-Sep-21	Healthwatch Milton Keynes		MK Pharmacy First – What is the rationale for the preferred option, to remove the service. Did that service actually save money? Has it costs money? Has it actually met the aims and objectives?				The number of patients seen through this service in Milton Keynes over the last three years is as follows: Year Patients seen 2018/19 8986 2019/20 7373 2020/21 2838* 2021/22 572 (Q1) Modelled full year: 2288 *Big drop in use with the pandemic being the contributing factor and a slight increase in GP prescriptions for items such as paracetamol. These numbers show a year on year decline on the use of this service, even prior to the Covid emergency, but clearly Covid has had a significant impact. The reduction in the numbers of patients using the service suggests that patients have been able to make alternative arrangements to obtain advice and medication, or that time-limited self-care has been possible with alternatively sourced over the counter medicine or without medication. Whether this has had an impact on ongoing health is not known, though it is worth noting that, by definition, the service is for minor ailments which are likely to resolve over a short period.	
06-Sep-21	Healthwatch Central Bedfordshire		Add a paragraph to the case for change to explain the governance process, that the Gov Body will make the final decision taking into account the views of the public collected during the consultation	Pg 5	Yes	Pg 5 How will a decision be made? When the public consultation closes, a report will be written which brings together all of the feedback received during the consultation and the analysis of the public survey. This report will be shared with the BLMK CCG Governing Body who at the public meeting in February 2022 will take into account the views of the public when they make their decision on which options will be taken forward and become policy for BLMK CCG.		
06-Sep-21	Healthwatch Central Bedfordshire		Make clear in the document that the consultation is not as a result of the Covid pandemic	Pg 2	No		The introduction articulates that the reason for the consultation is a need to align policies across BLMK	
06-Sep-21	Healthwatch Bedford Borough	What happens to those currently receiving fertility treatment? All patients accessing fertility treatment, or those who start fertility treatment under the current three policies, will continue to be entitled to the eligibility criteria within each policy for the area in which they reside. Once this consultation is complete and the new policy is agreed; the new criteria would be applied to all new requests for treatment.	Need to make sure the document is clear for people who have already been referred for Fertility Services that they will receive treatment under the current policies	Pg3	No	What happens to those currently receiving fertility treatment? All patients accessing fertility treatment, or those who start fertility treatment under the current three policies, will continue to be entitled to the eligibility criteria within each policy for the area in which they reside. Once this consultation is complete and the new policy is agreed; the new criteria would be applied to all new referrals for treatment.	There is already a paragraph that explains that patients will continue to receive treatment under current polcies if they are already under a referral.	
13-Sep-21	Bedford Borough OSC		When talking about Gluten Free foods, commitment was made to look at the wording around the clincial decision and prescriptions for vulnerable patients.	pg4	No		No change required as document includes the following explanation of how those at risk od dietary neglect are provided with access to gluten-free presriptions. 'The former Bedfordshire and Luton CCG areas have a process for those on universal credit (i.e. those most at risk from the loss of gluten-free food prescribing) to enable them to continue to access gluten-free food via community pharmacists. Within MK, the former CCG had an exceptional cases appeals process for those at risk of dietary neglect, which also allows patients at risk to continue to access these foods. It is not envisaged that this clinical decision will change for any area. Through an alignment of these processes those patients could still access these foods.'	
20-Sep-21	Internal Review	Option 2: To provide gluten-free bread and flour on prescription in Bedfordshire, Luton and Milton Keynes, to the value of £174,303 and seek to recover these costs by identifying cost savings in other service areas.	This is the only one of the options that uses that cost within the option text and appears to try to sway the reader	Pg4	For discussion	Option 2: To retain gluten-free bread and flour on prescription in Luton and provide the same access to gluten-free bread and flour in Bedfordshire and Milton Keynes.		
29-Sep-21	BLMK CCG Governing Body		Governing Body suggested that we should be clear in our consultation plan about how we will ensure fairness and range of responses			Consultation plan has been reviewed to ensure we are using all avaibale chanells to ensure BLMK residents are aware of the consultation.		
02-Oct-21	BLMK CCG Governing Body	As an organisation committed to principles of equality, diversity and inclusion we want to ensure equity of access. Following review by the BLMK Equality Diversity and Inclusion Group it is recommended that the fertility services policy entry point should be broadened to fund artificial insemination for same sex females, single females and transmen with uterus to ensure equity of access.	I have no issue with the numbers around fertility - it's the language	Pg 3	Yes	Following review by the BLMK Equality Diversity and Inclusion Group it is recommended that the fertility services policy entry point be broadened to provide access to specialist fertility services for same sex female couples, single females and any person with a uterus (Including trans men and non-binary people).		Changes made subsequent to the paper sumission deadline for Governing Body.
06-Oct-21	BLMK CCG Governing Body		Just to say that the national pharmacy contract has changed to incorporate the pharmacy first type schemes we perhaps should bring that out more	Pg 5	Yes	Content added on the National Pharmacy Scheme to the document		

General / all policies
Gluten Free / Pharmacy
Fertility

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17/08/2021	Quality & System Performance NHS South, Central and West	For specialist fertility the former MK and Bedfordshire areas offer one cycle,	We should be clear on what we mean with cycles, helpful approach could be perhaps to talk about fresh cycle and frozen cycle. It also looks better in the options if you offer just one fresh cycle that you can still have a frozen cycle i.e. two embryo transfers.		Yes	The definition of a full cycle has been added to the case for change appendix.		
		The access criteria have been reviewed by the BLMK Equality Diversity and Inclusion Group who have recommended that the IVF policy entry point should be amended to fund artificial insemination for same sex females, single females and transmen with uterus . This would see an increase in current spend (based on the current number of cycles per locality).	Perhaps we could avoid singling out any specific patient groups in here, as relationships may be complex. For example, trans female, in a gay relationship may have stored sperm and now they potentially have eggs and a womb just need to have AI and possibly need IVF. The paper uses the wording of 'trans or non-binary couples later on, maybe that would be broader approach. We could also be possibly looking to extend the access to people unable to have intercourse as per NICE CG suggestion: 'Consider unstimulated intrauterine insemination as a treatment option in the following groups as an alternative to vaginal sexual intercourse: •People who are unable to, or would find it very difficult to, have vaginal intercourse •Because of a clinically diagnosed physical disability or psychosexual problem who are •Using partner or donor sperm •People with conditions that require specific consideration in relation to methods of conception (for example, after sperm washing where the man is HIV positive) •People in same-sex relationships. [new 2013] For people in the above recommendation who have not conceived after 6 cycles of donor or partner insemination, despite evidence of normal ovulation, tubal patency and semenalysis, offer a further 6 cycles of unstimulated intrauterine insemination before IVF is considered. [new 2013]' Possible alternative wording for the groups covered in the policy (for improved access) same-sex couples, single women and trans or non-binary couples.		Yes	The appendix document has been updated to reflect these comments.		
		Equity of access will be increased, to reduce inequalities Number of cycles would be in line with geographical peers reducing "postcode lottery "	Unwarranted variation in access to care may be better term.		Yes	The appendix document has been updated to reflect these comments.		
		Equity of access will be increased, to reduce inequalities Number of cycles made available are in line with NICE Guidance	Just may need to add fresh cycles, otherwise this is not quite true for our options of one frozen transfer per fresh cycle. NICE definition of cycle is a fresh transfer and transfer of any resultant frozen embryos, so could be more than one frozen after the fresh cycle. NICE CG: What is a full cycle of IVF? A full cycle of IVF is one in which 1 or 2 embryos produced from eggs collected after ovarian stimulation are replaced into the womb as fresh embryos (where possible), with any remaining good quality embryos frozen for use later (see freezing embryos after IVF). When these frozen embryos are used later, this is still considered to be part of the same cycle.		Yes	The appendix document has been updated to reflect these comments.		
03-Sep-21	Operations Manager, Fertility Network UK	Known parental status	would a couple where one partner had an adult child living independently be seen in the same way as a couple with a young child living with them?		Yes	Couples are ineligible for treatment if there are any living children from the current or any previous relationships who they have contact with. 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.		
		Child Welfare	carrying out a welfare of the child assessment is mandatory under section 13(5) of theHuman Fertilisation and Embryology Act so it seems odd to include it in the criteria you are proposing to keep.		Yes	This has been removed form the criteria in the appendix document		
		Medical Conditions	what are the type of medical conditions that would lead you to deny treatment? I haven't come across this before.		No		E.g. cancer	
		Ovarian Reserve Testing, use FSH	you say here you are going to align to NICE guidance. NICE has no guidance on using ovarian reserve testing to determine who should have access to treatment. The guidelines on ovarian reserve are about response to ovarian stimulation. If you want to set guidance, you should be clear about where this comes from. Also, it would be good to see the evidence-base for recommending FSH rather than AMH and AFC.		Yes	This has been removed form the criteria in the appendix document		
		Maternal age and number of cycles	NICE guidance is quite specific about which women aged 40-42 should be eligible and it isn't clear here whether you will apply the general criteria used for access to treatment or the specific criteria for women in this age group?		Yes	The appendix document has been updated to reflect these comments.		
		Donor Insemination	wasn't quite clear what you were proposing here when aligning to NICE?		Yes	The appendix document has been updated to reflect these comments.		
		Chronic Viral Infections	It is important to be clear that needing any intervention for HIV patients is unusual. The vast majority of HIV patients have an undetectable viral load.		Yes	The appendix document has been updated to reflect these comments.		
		Embryo transfers	One cycle should not be two embryo transfers, but one cycle and the transfer of all remaining embryos.		Yes	The definition of a full cycle has been added to the case for change appendix.		
		Minimum / Maximum BMI	would be useful to have the evidence base for this.		No		The evidence used for this is NICE guidance.	
		Duration of sub-fertility	evidence base for 3 years for unexplained infertility? Wasn't sure here whether you going to offer treatment to all same sex female couples and single females regardless of fertility status and whether these figures had been modelled?		Yes	The appendix document has been updated to reflect these comments.		
03-Sep-21	Fertility Network UK		We get a lot of feedback on the previous child criteria, as there is a big difference between having a young child living with you to having a 25 yr old estranged child that lives abroad, so it is worth putting more detail in this criteria to help clarity.		Yes	Couples are ineligible for treatment if there are any living children from the current or any previous relationships who they have contact with. 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.		

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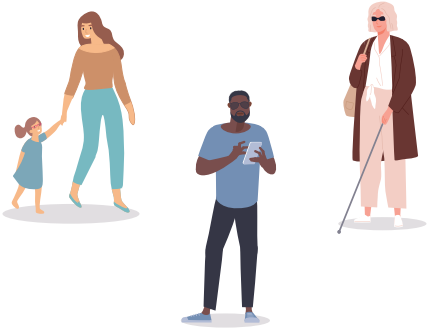
03-Sep-21	Fertility Network UK		You say that human rights are not relevant in the impact assessment, however there is a 1969 UN declaration on social progress and development which says that you should aim at the elimination of involuntary sterility so that all couples may be able to reach their desired number of children, so there is a Human rights element to it. WHO defines infertility as a disease and as a national health service we have a duty of care for any illness.		Yes	The QIAEADPIA has been updated to include: "Consideration of: The 1969 United Nations declaration on social progress and development which states "Ensure that family planning, medical and related social services aim not only at the prevention of unwanted pregnancies but also at the elimination of involuntary sterility and subfecundity in order that all couples may be permitted to achieve their desired number of children, and that child adoption may be facilitated". https://www.un.org/en/development/desa/population/theme/rights/index.asp The World Health Organisation defines infertility as a disease and as a national health service there is a duty of care for any illness. "Infertility is a disease of the male or female reproductive system defined by the failure to achieve a pregnancy after 12 months or more of regular unprotected sexual intercourse." https://www.who.int/news-room/fact-sheets/detail/infertility#:~:text=Infertility%20is%20a%20disease%20of,on%20their%20families%20and%20communities."		
01-Oct-21	BLMK CCG Governing Body		I agree with the point re inequality of access for financially disadvantaged people and I think it could come out more strongly in section 2.11 of the equality analysis.			Pharmacy First QIAEADPIA to be reviewed to take comment into account		

	General / all policies
	Gluten Free / Pharmacy
	Fertility



NHS
Bedfordshire, Luton and Milton Keynes
Clinical Commissioning Group

Public Consultation
Aligning policies across Bedfordshire, Luton and Milton Keynes

Case for Change

Consultation runs from
Tuesday 12 October 2021 to Tuesday 21 December 2021

Background - Who are we?

NHS Bedfordshire, Luton and Milton Keynes Clinical Commissioning Group (BLMK CCG) was formed on 1 April 2021 following the merger of Bedfordshire Clinical Commissioning Group (BCCG), Luton Clinical Commissioning Group (LCCG) and Milton Keynes Clinical Commissioning Group (MKCCG).

We are responsible for planning, organising and buying NHS-funded healthcare for the almost 1 million people living in BLMK. This includes hospital services, community health services, community pharmacies and mental health services.

BLMK CCG is run by GPs, nurses, hospital doctors and other clinicians - the people you see whenever you come into contact with the NHS. All 96 GP practices across Bedfordshire, Luton and Milton Keynes are members of the CCG.

We are committed to delivering local, high-quality healthcare services while making sure we achieve the best value for money and equity of access for our growing population.

What is this document about?

In 2021 the three former Clinical Commissioning Groups, Bedfordshire, Luton and Milton Keynes, merged to become BLMK CCG. As we came together, we reviewed the policies that each of the former CCG's held. For the most part there was considerable commonality across the policies, but three policies had marked differences. These policies relate to:

- **Fertility Services**
- **Gluten-Free Food Prescribing**
- **Milton Keynes Pharmacy First Minor Ailment Scheme**

In order to provide equal access to services across BLMK we need to move to a single policy for each service.

This document provides information so that you can understand and then respond to the following proposals:

Fertility Services - Make fertility services available to a broader group of residents (including those with specific protected characteristics to whom the service was not previously available) to ensure equal access to the service. This will include a review of the number of cycles of In-Vitro Fertilisation (IVF) available.

Bringing all the three former CCG areas in line regarding access to:

- **Pharmacy First Minor Ailment Scheme** (currently only available in Milton Keynes)

- **Gluten-Free Food Prescribing** (currently only access to bread and flour and only available in Luton)

On the next few pages you will find further detail on each of the service areas to help you help us make these important decisions.

Fertility Services

Fertility Services support people who have not been able to conceive naturally. These specialist fertility services are considered as level three services, or tertiary services and are accessible to people who have completed preliminary investigations and treatments in primary care and secondary care.

Treatments delivered by specialist fertility services include:

- In-vitro fertilisation (IVF) and Intra-cytoplasmic sperm injection (ICSI)
- Surgical sperm retrieval methods (SSR)
- Donor Insemination (DI)
- Intra Uterine Insemination (IUI) unstimulated
- Sperm, embryo and male gonadal tissue cryostorage and replacement techniques
- Egg donation where no other treatment is available
- Blood borne viruses (ICSI + sperm washing)

BLMK CCG currently has in place three policies covering specialist fertility services - one for each of the former CCG areas (Bedfordshire, Luton and Milton Keynes).

The eligibility criteria within the policies vary, some align through all three policies, some have small differences and some of them are vastly different. A detailed piece of work has been undertaken to map and understand the differences and work through how to bring the policies together as one. Clinical discussions have been held about what the criteria should look like moving forward. A full list of the criteria, the differences and our proposals can be found at Appendix A.

There is also variation between the number of IVF cycles that are currently available for patients; Bedfordshire and Milton Keynes offer one cycle of IVF treatment whilst Luton offers three.

There is a real need to balance funding for this treatment with all other treatments and services across the NHS in Bedfordshire, Luton and Milton Keynes. The CCG's current annual spend on fertility services is £895,264 - an average cost per patient of £1,865. During 2019/2020, 480 people across BLMK accessed IVF treatment, this is approximately 0.05% of the BLMK population.

The Luton policy of routinely offering up to three cycles is at odds with the majority of the surrounding CCG Areas. Within the East of England health region, only Thurrock and the former Luton CCG offer more than one cycle. All others offer one cycle and in the wider geography, Oxfordshire, Buckinghamshire and Berkshire CCGs all offer one cycle.

The National Institute for Health and Care Excellence (NICE) develop guidelines for health and care services in England. Guidelines are provided for fertility services however these are recommendations only and need to be considered within a local context when commissioning services.

Access Criteria

As an organisation committed to principles of equality, diversity and inclusion we want to ensure equity of access. Following review by the BLMK Equality Diversity and Inclusion Group it is recommended that the fertility services policy entry point be broadened to provide access to specialist fertility services for same sex female couples, single females and any person with a uterus (including trans men and non-binary people).

What is the cost of fertility services to BLMK CCG?

The CCG's current annual spend on fertility services is £895,264. If the number of cycles was aligned to three across BLMK this would increase to at least £1,670,149, an increase of £774,845. As the CCG has a finite financial resource, this would require a review of budget allocation. If the number of cycles were to be aligned to one across BLMK and the groups eligible to access services widened, we do not anticipate any significant change in current costs.

What happens to those currently receiving fertility treatment?

All patients accessing fertility treatment, or those who start fertility treatment under the current three policies, will continue to be entitled to the eligibility criteria within each policy for the area in which they reside. Once this consultation is complete and the new policy is agreed; the new criteria will be applied to all new referrals for treatment.

Options for Consultation

As part of this consultation, we are seeking views on the following options for IVF Treatment:

Option 1: To reduce the current offer of three cycles of IVF to residents in Luton to one cycle for all eligible patients, in line with the current offering in Bedfordshire and Milton Keynes and extend access to the service for same sex female couples, single females and any person with a uterus (including trans men and non-binary people), who are currently unable to access fertility services under existing policies.

Option 2: To increase the number of cycles in Bedfordshire and Milton Keynes to three cycles for all patients aged 39 and under, and one cycle for all eligible patients aged 40-42, in line with the current Luton model and extend access to the service to same sex female couples, single females, and any person with a uterus (including trans men and non-binary people), who are currently unable to access fertility services under existing policies.

Our preferred option is Option 1: To reduce the current offer of three cycles of IVF to residents in Luton to one cycle for all eligible patients, in line with the current offering in Bedfordshire and Milton Keynes and extend access to the service to same sex female couples, single females, and any person with a uterus (including trans men and non-binary people).

This takes into account our commitment to address unwarranted variation in access, both in BLMK and in the wider region, working within the constraints of the wider BLMK CCG health budget.

Gluten-free Foods

Gluten is a type of protein that is found in three types of cereal - wheat, barley and rye. A gluten-free diet is recommended for people who have been clinically diagnosed with coeliac disease. Gluten can cause symptoms that include bloating, diarrhoea, nausea, tiredness and headaches.

Certain foods are naturally gluten-free such as meat, vegetables, cheese, potatoes and rice. Gluten-free alternatives for those foods that do traditionally contain gluten, such as bread and pasta, are available to those who wish to continue to eat similar foods which contain the cereals described.

There is no cure for coeliac disease but switching to a gluten-free diet will help control symptoms.

A decision was taken over 30 years ago to include gluten-free foods on prescription, when there was limited availability of gluten-free foods to buy. Today the availability of gluten-free foods has significantly increased and they are found in almost all major supermarkets.

There is a lot of information available to patients via their GP, dietitian or available online about how to eat a healthy gluten-free diet.

When prescribing gluten-free foods the NHS pays both for the food plus the additional cost of processing the prescriptions. The cost of administering the service is estimated at £10 per patient, per month.

In 2018, a national consultation on gluten-free food prescribing was undertaken, the outcome of which was that the service would restrict gluten-free prescriptions to a staple list of gluten-free bread and mix products.

Under the new legislation, CCGs retained individual responsibility to be able to restrict further by selecting bread only, mixes only or choose to end prescribing of all gluten-free foods if they feel this is appropriate for their population, whilst taking account of their legal duties to advance equality and have regard to reducing health inequalities.

Currently, Gluten-free food prescribing is only routinely available in the former Luton CCG area and only supplies bread and flour on prescription. Prescribing is available to any patient diagnosed with Coeliac disease or dermatitis herpetiformis and currently covers approximately 100 patients.

The former Bedfordshire and Luton CCG areas have a process for those on universal credit (i.e. those most at risk from the loss of gluten-free food prescribing) to enable them to continue to access gluten-free food via community pharmacists. Within Milton Keynes, the former CCG had an exceptional cases appeals process for those at risk of dietary neglect, which also allows patients at risk to continue to access these foods. It is not envisaged that this clinical decision will change for any area.Through an alignment of these processes those patients could still access these foods.

The following figures show a modelled full year impact, the total in the first column shows the current spend for gluten-free prescribing as £54,705. The total in the second column shows the predicted spend if gluten-free prescribing were to be extended to the Bedfordshire and Milton Keynes populations. This is an increase of £174,303 which would be an overall cost of £229,008.

Gluten Free Prescribing modelling - roll out Luton approach		
	Current spend	**Modelled at current population**
MKCCG	£1,408	£66,622
LCCG	£52,899	£52,899
BCCG	£398	£109,487
Total	**£54,705**	**£229,008**
Increase from current spend:		**£174,303**

Options for Consultation

As part of this consultation, we are seeking views on the following options for gluten-free food prescribing:

Option 1: To withdraw the gluten-free bread and flour available on prescription in Luton whilst ensuring patients at risk of dietary neglect are still able to access when appropriate, in line with Bedfordshire and Milton Keynes.

Option 2: To retain gluten-free bread and flour on prescription in Luton and provide the same access to gluten-free bread and flour in Bedfordshire and Milton Keynes.

Our preferred option is Option 1: To withdraw the gluten-free bread and flour available on prescription in Luton, whilst ensuring patients at risk of dietary neglect are still able to access when appropriate, in line with Bedfordshire and Milton Keynes.

This takes into account our commitment to address inequality of access across BLMK whilst ensuring patients at risk of dietary neglect are still able to access gluten-free bread and flour on prescription if clinically appropriate. Option 1 would also create a small financial saving benefitting the wider BLMK CGG health budget.

Milton Keynes Pharmacy First Minor Ailment Scheme

Milton Keynes Pharmacy First Minor Ailment Scheme is a service provided in some pharmacies in Milton Keynes and only available to registered patients in the former Milton Keynes CCG area. It provides pharmacist advice on minor ailments and also supplies Over the Counter (OTC) medication free of charge to people who qualify for free prescriptions. The scheme was implemented to reduce demand for primary care and A&E. This scheme has never existed in Bedfordshire and Luton.

All other CCGs in the East of England follow the national position of encouraging self-care advice and guidance and do not provide this service. The Minor Ailment Service was implemented following a pilot in 2006, this was followed by the Pharmacy First Scheme in April 2018, recent guidance from NHS England together with the National Community Pharmacy Consultation Scheme now places greater emphasis on the importance of self-care. Recently some Pharmacies in Milton Keynes have opted out of the Pharmacy First Scheme, in favour of the national scheme.

It should be emphasised that all patients of BLMK CCG have access to the nationally commissioned "Community Pharmacy Consultation Scheme" (CPCS), which allows referral direct from practice (typically the prescription clerk) for patients who require a consultation for minor illness, without having to go through the GP first. Through this scheme, community pharmacists provide advice and guidance to enable the patient to self-care and/or purchase OTC medication. Likewise, patients can attend community pharmacy for advice without an appointment and purchase OTC medication in line with NHS guidance.

The number of patients seen through the Pharmacy First Scheme in Milton Keynes over the last three years is as follows:

Year	Patients seen
2018/19	8986
2019/20	7373
2020/21	2838*
2021/22	572 (Q1) Modelled full year: 2288

*We saw a considerable drop in use with the pandemic being the contributing factor and only a slight increase in GP prescriptions for items such as paracetamol.

These numbers show a year-on-year decline on the use of this service, even prior to the Covid emergency, but clearly Covid has had a significant impact. The reduction in the numbers of patients using the service suggests that patients have been able to make alternative arrangements to obtain advice and medication, or that time-limited self-care has been possible with alternatively sourced over the counter medicine or without medication. Whether this has had an impact on ongoing health is not known, though it is worth noting that, by definition, the service is for minor ailments which are likely to resolve over a short period.

A full list of which self-care items are available through the Pharmacy First Minor Ailment Scheme can be seen on the consultation web page at **www.blmkccg.nhs.uk/PolicyConsultation**

The following figures show a modelled full year impact, the total in the first column shows the current spend for the Pharmacy First Minor Ailment scheme in Milton Keynes as £25,011. The total in the second column shows the predicted spend if the scheme were to be extended to the Bedfordshire and Luton populations. This would be an increase of £60,962 with a total cost of £85,973.

Roll out Pharmacy First - modelling		
	Current spend	**Modelled at current population**
MKCCG	£25,011	£25,011
LCCG	0	£19,859
BCCG	0	£41,103
Total	**£25,011**	**£85,973**
Increase from current spend:		**£60,962**

Options for Consultation

As part of this consultation, we are seeking views on the following options for the Pharmacy First Minor Ailment Scheme:

Option 1: To withdraw the Pharmacy First Minor Ailment Scheme in Milton Keynes to align this service with the current offering in Bedfordshire and Luton.

Option 2: To retain the Pharmacy First Minor Ailment Scheme in Milton Keynes and expand to include Bedfordshire and Luton.

Our preferred option is Option 1: To withdraw the Pharmacy First Minor Ailment Scheme in Milton Keynes to align this service with the current offering in Bedfordshire and Luton.

This takes into account our commitment to address inequality of access across BLMK and encourages all residents to access the nationally commissioned "Community Pharmacy Consultation Scheme" (CPCS).

Policies

Full policy documents for each of the former CCG areas can be viewed on our website at:
www.blmkccg.nhs.uk/PolicyConsultation

Individual Funding Request (IFR) Process
For all of the above proposals it should be noted that the Individual Funding Request (IFR) process is still available for patients. Funding requests are reviewed and decided upon by a panel but applications will only be taken forward if there are exceptional clinical circumstances.

IFR applications need to be made on behalf of the patient by a clinician.

Further information can be found on BLMK CCG's website: **https://www.blmkccg.nhs.uk/your-health/individual-funding/**

How will a decision be made?

When the public consultation closes, a report will be written which brings together all of the feedback received during the consultation and the analysis of the public survey. This report will be shared with the BLMK CCG Governing Body, who at the public meeting in February 2022 will take into account the views of the public when they make their decision on which options will be taken forward and become policy for Bedfordshire, Luton and Milton Keynes.

How can I give my views?

We would like to hear your views on the proposed options for the three policies.

Please complete the accompanying survey to this booklet and post back to us by **Tuesday 21 December 2021** (no stamp needed).

Alternatively, you can complete the questionnaire online at: **www.blmkccg.nhs.uk/PolicyConsultation**

This QR code takes you to our website

Further information about how you can share your views can be found online at: **www.blmkccg.nhs.uk/PolicyConsultation**

The formal consultation commences on Tuesday 12 October 2021 and ends on Tuesday 21 December 2021.

If you would like any of the supporting documents for the consultation in paper copy please call 01525 624264 or email **blmkccg.communications@nhs.net.**

The consultation feedback will be evaluated with a recommendation to Bedfordshire, Luton and Milton Keynes CCG Governing Body in February 2022.

Once complete, the results will be available on the BLMK CCG website.

Do you need this document in a different format?

For alternative formats please call **01525 624264**
or email **blmkccg.communications@nhs.net**

Bedfordshire, Luton and Milton Keynes
Clinical Commissioning Group (BLMK CCG)
Email: **blmkccg.communications@nhs.net**
Website: **www.blmkccg.nhs.uk**

Reference: 327/BLMK/POLICY/Oct2021

Appendix A – List of Criteria for Fertility Services Policy:

No change to criteria in the existing 3 policies:

Criteria	Explanation of existing policies	BLMK proposed alignment
Previous sterilisation	Current policies align on previous sterilisation and include criteria that treatment is not offered to couples if previous sterilisation has taken place, even if reversed.	BLMK CCG is proposing to keep the current criteria around previous sterilisation.
Medical Conditions	Current policies align on the medical conditions criteria which stipulates that "Treatment may be denied on other medical grounds not explicitly covered in this document."	BLMK CCG is proposing to keep the current criteria around medical conditions.
Donor eggs and donor sperm	Current policies cover use of donors eggs and donor sperm under specific criteria.	BLMK CCG is not proposing to change this element of the policies.
Surrogacy	The 3 policies are similar and state that surrogacy is not covered under the policy.	For the purposes of this policy, surrogacy is a female external to the couple being used to carry a pregnancy on behalf of the couple where there are medical reasons where the female is unable to carry. The CCG does not fund surrogacy; this includes part funding during a surrogacy cycle. Individuals may be eligible for appropriate investigation where there is evidence of subfertility.

Where BLMK propose to align to NICE guidelines:

Criteria	Explanation of existing policies	BLMK proposed alignment
Ovarian Reserve Testing, use FSH	There are very minor variations between existing policies in relation to the Ovarian Reserve Testing measure - follicle-stimulating hormone (FSH). In LCCG and MKCCG FSH is required to be less than 8.9 and in BCCG less than 9.0.	BLMK CCG is proposing to align to NICE guidelines for this criteria i.e. the patient should have a follicle-stimulating hormone (FSH) of less than 8.9.
Maternal age and number of cycles:	Current policies vary on the number of cycles offered. BCCG and MKCCG offer 1 full cycle but LCCG offer 3 cycles for women under the age of 40. BCCG do not offer any cycles to women aged 40-42 whereas LCCG and MKCCG offer 1 cycle to women aged 40-42.	BLMK CCG is proposing to implement the number of cycles as per the outcome of this consultation. BLMK CCG is proposing to apply NICE guidelines in relation to age criteria for service users (e.g. patients up to the age of 42 will be eligible and the existing minimum age of 23 years stated in the existing BCCG and LCCG policies should be removed).

Criteria	Explanation of existing policies	BLMK proposed alignment
Chronic Viral Infections	Managing the risk of transmission of chronic viral infections is described in the LCCG and BCCG policies, but not in the MKCCG policy.	BLMK CCG is proposing to provide the following clarification: This may not be a fertility treatment, but should be considered as a risk reduction measure for a couple or individual who wish to have a child, but do not want to risk the transmission of a serious pre-existing viral condition to their partner and therefore potentially the unborn baby. As there is a need to prevent the transmission from partner to partner of chronic viral infections, during conception, such as HIV, Hep C etc. any decision about fertility management should be the result of discussions between the couple, a fertility specialist and an HIV specialist where appropriate. (Ref: NICE Guideline cg156 (2013) 1.3.9 and 1.3.10.)

BLMK proposed alignment of remaining criteria:

Criteria	Explanation of existing policies	BLMK proposed alignment
Known Parental Status	Current policies align on known parental status and include the criteria that treatment is not offered to couples if there are any living children from the current or any previous relationships, regardless of whether the child resides with them. This includes any adopted child within their current or previous relationships.	BLMK CCG is proposing to alter the criteria to: Couples are ineligible for treatment if there are any living children from the current or any previous relationships who they have contact with. 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.

Criteria	Explanation of existing policies	BLMK proposed alignment
Embryo transfers	Current policies vary on the number of embryo transfers between maximum of 2 in MKCCG and BCCG, up to 6 in LCCG.	BLMK CCG is proposing to implement the number of embryo transfers in line with the number of cycles agreed as per the outcome of this consultation. e.g. 1 cycle offered = 2 embryo transfers (1 fresh and 1 frozen). 3 cycles offered = 6 embryo transfers (3 fresh and 3 frozen).
Paternal Age	The only existing policy to include a paternal age limit is BCCG which stipulates that "treatment must be commenced before the male is 55 years of age".	BLMK CCG is proposing that no paternal age limit would be included in the future policy.
Minimum / Maximum BMI	Current policies vary slightly on the minimum Body Mass Index (BMI) for females. In LCCG and BCCG the minimum requirement is 19 for females, however in MKCCG there is no minimum. All three policies are aligned on the maximum BMI (30) for females. In LCCG and BCCG male BMI is required to be less than 35. No maximum is stated for males in the MKCCG policy.	BLMK CCG are proposing that BMI should be between at least 19 and up to 30 for female and less than 35 for males.

Criteria	Explanation of existing policies
Duration of sub-fertility	Duration of sub-fertility varies between the three existing policies and between age groups. LCCG and BCCG stipulate 3 years or more of regular intercourse or an equivalent 12 self-funded cycles of Intra-Uterine Insemination (IUI) over a period of 3 years for unexplained infertility, and 2 years for MKCCG.

BLMK proposed alignment

BLMK CCG are proposing the following:

Where a female or any person with a uterus is of reproductive age and having regular unprotected vaginal intercourse two to three times per week, failure to conceive within 12 months should be taken as an indication for further investigation.

If the female or any person with a uterus is aged 36 or over then such investigation should be considered after 6 months of unprotected regular vaginal intercourse since their chances of successful conception are lower and the window of opportunity for intervention is less.

Couples with unexplained infertility or mild male factor infertility/subfertility must have infertility of at least 2 years of ovulatory cycles, despite regular unprotected vaginal sexual intercourse.

Females aged 40 to 42 years, who have not conceived after 2 years of regular unprotected vaginal intercourse, will be eligible for treatment as long as other criteria in this policy are met.

Couples with a diagnosed cause of absolute infertility which precludes any possibility of natural conception, including same sex female couples and single females, or any person with a uterus (including trans men and non-binary people) and who meet other eligibility criteria will have immediate access to NHS funded assisted reproduction services.

Where mild male factor infertility has been diagnosed evidence should be provided to demonstrate that any underlying treatable cause has been investigated and ruled out.

Criteria	Explanation of existing policies	BLMK proposed alignment
Smoking Status	Current policies vary on the length of time which constitutes non-smoking status, however all apply non-smoking as a criteria for treatment.	BLMK CCG are proposing to keep non-smoking status as a criteria for treatment and align the measure of non-smoking.
Residential Status	Current policies vary on residential status. Under LCCG policy couples should be registered with a LCCG GP for 12+ months. Under BCCG policy couples should be either registered with BCCG GP for 12+ months or registered with a GP within the East of England Consortium Fertility Service Clinical Group for 12+ months. MKCCG does not state any residential status.	BLMK CCG is proposing to stipulate that those accessing the service should be registered with a GP in BLMK CCG for 12+ months and currently reside within the BLMK area.
Rubella Status	Current policies vary on the requirement for service users to be rubella immune. BCCG and LCCG require woman to be rubella immune however MKCCG does not state.	Rubella is very serious if a pregnant person catches it in the early stages of pregnancy, because it can profoundly damage the unborn child. BLMK CCG are proposing that rubella immunity testing will be carried out at primary care investigation stage.

Criteria	Explanation of existing policies	BLMK proposed alignment
Patients who have social, cultural or religious objections to IVF	Intra-Uterine Insemination (IUI) is stated in the current policies as a replacement for IVF/ICSI and without donor sperm under exceptional circumstances and an IFR/ITP application for funding has been made. As with IVF cycles this varies across the three policies with BCCG and MKCCG offering 1 cycle but LCCG offering 3 cycles for women under the age of 40. BCCG do not offer any cycles to women aged >40, whereas LCCG and MKCCG offer 1 cycle to women aged >40.	BLMK CCG is proposing to implement the number of IUI cycles in line with the number of IVF cycles agreed as per the outcome of this consultation. e.g. 1 cycle of IVF offered = 3 cycles of IUI offered. 3 cycles of IVF offered = 9 cycles of IUI offered. This would still be applicable under exceptional circumstances and an IFR application for funding has been made.
Women in same-sex couples, single women and couples not able to have vaginal intercourse	Current policies vary for same sex couples. LCCG offer IVF treatment following 6 cycles of self-funded IUI. MKCCG offer IVF treatment to same sex couples who meet other eligibility criteria. BCCG does not mention same sex couples.	Women in same-sex couples (where one of the couple has a uterus), single women and couples not able to have vaginal intercourse are entitled to NHS funded IVF treatment following 6 cycles of NHS funded donor IUI. BMI eligibility criteria above apply only to the female partner or person with a uterus undergoing the fertility treatment.

Criteria	Explanation of existing policies	BLMK proposed alignment
Women in same-sex couples, single women and couples not able to have vaginal intercourse		The partner of a person who has undertaken NHS funded fertility treatment, whether successful or not, will be deemed to have received their entitlement to NHS funded fertility treatment upon completion of their treatment, in line with the criteria for heterosexual couples and will not be eligible for additional cycles with their partner or any future partners. Couples will be required to fit all other criteria within a policy in line with heterosexual couples.

Glossary:

Cycle of IVF - "A full cycle of IVF is one in which 1 or 2 embryos produced from eggs collected after ovarian stimulation are replaced into the womb as fresh embryos (where possible), with any remaining good quality embryos frozen for use later (see freezing embryos after IVF). When these frozen embryos are used later, this is still considered to be part of the same cycle."

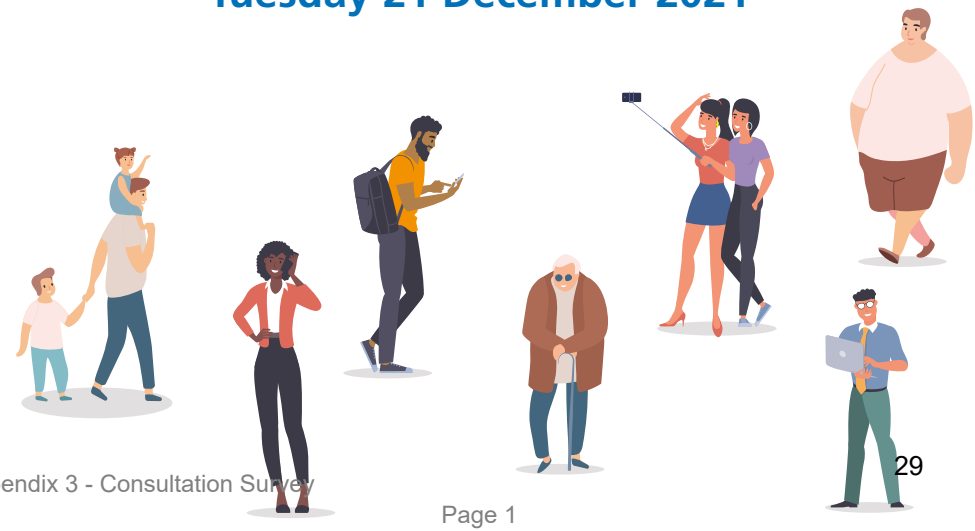
Abandoned / cancelled cycle of IVF - "An abandoned fresh cycle is one where ovarian stimulation begins but does not culminate in an embryo transfer. An abandoned frozen cycle is one where hormone treatment is started but does not culminate in an embryo transfer."

NHS
Bedfordshire, Luton and Milton Keynes
Clinical Commissioning Group

Public Consultation
Aligning policies across Bedfordshire, Luton and Milton Keynes

Survey

Consultation runs from
Tuesday 12 October 2021 to Tuesday 21 December 2021



Introduction

NHS Bedfordshire, Luton and Milton Keynes Clinical Commissioning Group (BLMK CCG) was formed on 1 April 2021 following the merger of Bedfordshire Clinical Commissioning Group (BCCG), Luton Clinical Commissioning Group (LCCG) and Milton Keynes Clinical Commissioning Group (MKCCG).

We are responsible for planning, organising and buying NHS-funded healthcare for the almost 1 million people living in BLMK. This includes hospital services, community health services, community pharmacies and mental health services.

Consultation Survey

What do you think about our proposal?

We would like to hear your views on our proposal to provide equal access to services across BLMK and to move to a single policy for each service. The consultation document provides information so that you can understand the differences between the policies.

Please complete the following questionnaire to share your views. The questionnaire will remain open until midnight on Tuesday 21 December 2021. Full details of the consultation can be viewed at **www.blmkccg.nhs.uk/PolicyConsultation**

In order to ensure full analysis of the answers, please complete all questions.

This QR code takes you to our website

Please tell us your views

1. Which of the following areas do you have a specific interest in? (tick all that apply)

- ☐ Gluten-free food prescribing
- ☐ Milton Keynes Pharmacy First Minor Ailment Scheme
- ☐ Specialist fertility services
- ☐ The way in which the local health budget is spent

2. Which local authority area do you reside in? (tick one box only)

- ☐ Bedford Borough
- ☐ Central Bedfordshire
- ☐ Luton
- ☐ Milton Keynes
- ☐ Other (please specify)

3. Please provide the first part of your postcode

☐ ☐ ☐ ☐ ☐ ☐

Fertility Services

4. What is your interest in Fertility Services? (tick one box only)

- ☐ Member of the public currently accessing fertility services
- ☐ Member of the public who has accessed fertility services in the past
- ☐ A relative of someone who is receiving/has received fertility services in the past
- ☐ A member of the public who thinks they may need fertility services in the future
- ☐ A BLMK GP/Clinician
- ☐ An NHS Provider
- ☐ A representative from the voluntary/support sector
- ☐ An interested member of the public
- ☐ Other (please specify)

5. Which of the following options do you think BLMK CCG should opt for when commissioning Fertility Services for the future? Please see next page for options.

Please tick one option

☐ **Option 1**

To reduce the current offer of three cycles of IVF to residents in Luton to one cycle for all eligible patients, in line with the current offering in Bedfordshire and Milton Keynes and extend access to the service for same sex female couples, single females and any person with a uterus (including trans men and non-binary people), who are currently unable to access fertility services under existing policies.

☐ **Option 2**

To increase the number of cycles in Bedfordshire and Milton Keynes to three cycles for all patients aged 39 and under, and one cycle for all eligible patients aged 40-42, in line with the current Luton model and extend access to the service to same sex female couples, single females, and any person with a uterus (including trans men and non-binary people), who are currently unable to access fertility services under existing policies.

6. **Would you like to comment on any of the other eligibility criteria for Fertility Services, as set out in Appendix A of the Case for Change document and also online at: www.blmk.nhs.uk/PolicyConsultation**

Gluten-free food prescribing

7. What is your interest in gluten-free food prescribing? (tick one box only)

- ☐ Member of the public currently accessing gluten-free food on prescription
- ☐ Member of the public who has accessed gluten-free food on prescription in the past
- ☐ A relative of someone who is receiving/has received gluten-free food on prescription in the past
- ☐ A BLMK GP/Clinician
- ☐ An NHS Provider
- ☐ A representative from the voluntary sector
- ☐ An interested member of the public
- ☐ Other (please specify)

8. Which of the following options do you think BLMK CCG should opt for when commissioning gluten-free food on prescription for the future?

Please tick one option

☐ **Option 1**

To withdraw the gluten-free bread and flour available on prescription in Luton whilst ensuring patients at risk of nutritional harm are still able to access when appropriate, in line with Bedfordshire and Milton Keynes.

☐ **Option 2**

To retain gluten-free bread and flour on prescription in Luton and provide the same access to gluten-free bread and flour in Bedfordshire and Milton Keynes.

9. Are there any other comments you would like to make regarding gluten-free food on prescription?

Milton Keynes Pharmacy First Minor Ailment Scheme

10. What is your interest in Milton Keynes Pharmacy First Ailment Scheme? (tick one box only)

- ☐ Member of the public currently currently accessing the Milton Keynes Pharmacy First Minor Ailment Scheme
- ☐ Member of the public who has accessed the Milton Keynes Pharmacy First Minor Ailment Scheme
- ☐ A relative of someone who is receiving/has received the Milton Keynes Pharmacy First Minor Ailment Scheme in the past
- ☐ A BLMK GP/Clinician
- ☐ An NHS Provider
- ☐ A representative from the voluntary sector
- ☐ An interested member of the public
- ☐ Other (please specify)

11. Which of the following options do you think BLMK CCG should opt for when commissioning the Pharmacy First Minor Ailment Scheme. Please see next page for options.

Please tick one option

☐ **Option 1**

To withdraw the Pharmacy First Minor Ailment Scheme in Milton Keynes to align this service with the current offering in Bedfordshire and Luton.

☐ **Option 2**

To retain the Pharmacy First Minor Ailment Scheme in Milton Keynes and expand to include Bedfordshire and Luton.

12. Are there any other comments you would like to make regarding the Pharmacy First Minor Ailment Scheme?

13. Please provide us with any other comments regarding this public consultation.

About you

Bedfordshire, Luton and Milton Keynes Clinical Commissioning Group is committed to delivering excellent services, but we can only do this if we understand our patients and their needs.

We would be grateful if you could please tell us a little more about yourself to help us understand whether we have heard from a mix of people and to help us consider any consistent feelings that may be expressed by different groups.

This section is not compulsory, and your views will still be taken into account should you choose not to fill it in.

All information will be kept strictly confidential and in accordance with the Data Protection Act and GDPR guidance.

14. What age group do you belong to?

- ☐ Under 18 years
- ☐ 18 to 24
- ☐ 25 to 34
- ☐ 35 to 44
- ☐ 45 to 54
- ☐ 55 to 64
- ☐ 65 to 74
- ☐ 75 to 84
- ☐ 85 or older
- ☐ Prefer not to say

15. Do you consider yourself to have a disability?

- ☐ Yes
- ☐ No
- ☐ Prefer not to say

16. If you answered yes to question 15, please indicate the nature of your disability (if you answered no, please leave this question blank).

- ☐ Learning disability
- ☐ Long term mental health condition
- ☐ Physical impairment
- ☐ Blind/sight impairment
- ☐ D/deaf or hearing impairment
- ☐ Other long term condition, please specify

17. What is your gender?

- ☐ Male
- ☐ Female
- ☐ Transgender
- ☐ Non-binary
- ☐ Intersex
- ☐ Prefer not to say
- ☐ Prefer to self-describe, please specify

18. Are you currently pregnant, have given birth within the last two weeks, or on maternity leave?

- ☐ Yes
- ☐ No
- ☐ Prefer not to say/not applicable

19. Have you been through the process, or are considering, gender reassignment?

- ☐ Yes
- ☐ No
- ☐ Prefer not to say

20. Which of the following best describes your sexual orientation?

- ☐ Bisexual
- ☐ Gay or Lesbian
- ☐ Heterosexual/straight
- ☐ Prefer not to say
- ☐ Other sexual orientation, please specify

21. What is your legal marital or civil partnership status?

- ☐ Co-habiting
- ☐ In a civil partnership
- ☐ Married
- ☐ Single
- ☐ Widowed
- ☐ Prefer not to say

22. What is your ethnic group?

(A) White

- ☐ English, Welsh, Scottish, Northern Irish or British
- ☐ Irish
- ☐ Gypsy or Irish Traveller
- ☐ Roma
- ☐ Any other White background, please specify

(B) Mixed

- ☐ White and Black Caribbean
- ☐ White and Black African
- ☐ White and Asian
- ☐ Any other mixed ethnic background, please specify

(C) Asian or Asian British

- ☐ Indian
- ☐ Pakistani
- ☐ Bangladeshi
- ☐ Chinese
- ☐ Any other Asian background, please specify

(D) Black or Black British

- ☐ African
- ☐ Caribbean
- ☐ Any other Black background, please specify

E) Other ethnic group

- ☐ Arab
- ☐ Any other, please specify

F) Prefer not to say

- ☐ Prefer not to say

23. What is your religion?

- ☐ No religion
- ☐ Atheist
- ☐ Buddhist
- ☐ Christian (including Church of England, Catholic, Protestant and all other Christian denominations)
- ☐ Hindu
- ☐ Jewish
- ☐ Muslim
- ☐ Sikh
- ☐ Any other religion, please specify

Thank you completing our survey

Please let us know if you would like BLMK CCG to contact you with the results of this consultation:

☐ Please send me the results of this consultation

☐ No, I do not wish to be contacted

If you wish to receive the results of this consultation, please provide your contact details;

Your name

Your email address

If you do not have an email address and would like to receive the results please call **01525 624264** and leave your contact details.

Appendix 4

BLMK CCG Policy Alignment Public Consultation

Engagement Log	
Date	**Activity**
12/10/21	Launched on website https://www.blmkccg.nhs.uk/get-involved/consultation-and-engagement/engagement-opportunities/blmk-policy-consultation/
12/10/21	Issued a media release to promote public consultation https://www.blmkccg.nhs.uk/local-nhs-asking-residents-to-get-involved-and-share-their-views/
12/10/21	Launched social media campaign (see separate log)
12/10/21	Information included in primary care news bulletin shared with GP practices across BLMK
15/10/21	BBC Look East interview with Dr Shankari Maha (shown on BBC Look East (West) at 6.30pm and 10pm)
15/10/21	Email to members of BLMK CCG TILT to advise consultation launched
15/10/21	Email to local Healthwatch organisations with links to online content and A5 flyer as attachment, with request to share via networks
19/10/21	Email to local Maternity Voice Partnerships (MVPs) informing them of the consultation and request to share with networks (attached poster, flyer, suggested text for newsletter, links to CCG social media platforms)
19/10/21	Email to local Fertility centres informing them of the consultation and request to share with networks (attached poster, flyer, suggested text for newsletter, links to CCG social
19/10/21	Email to local women's groups informing them of the consultation and request to share with networks (attached poster, flyer, suggested text for newsletter, links to CCG social media platforms)
19/10/21	Email to local LGBTQ groups informing them of the consultation and request to share with networks (attached poster, flyer, suggested text for newsletter, links to CCG social media platforms)
19/10/21	Email to local support organisations informing them of the consultation and request to share with networks (attached poster, flyer, suggested text for newsletter, links to CCG social media platforms)
19/10/21	Email to local Foodbanks informing them of the consultation and request to share with networks (attached poster, flyer, suggested text for newsletter, links to CCG social media platforms)
19/10/21	Emails to Community Centres across Bedford Borough, Milton Keynes and Luton informing them of the consultation and request to share with networks (attached poster, flyer, suggested text for newsletter, links to CCG social media platforms)
19/10/21	Information sent to practice managers to share with their PPGs in Bedfordshire, Luton and Milton Keynes (Paragraph of text with link to consultation page and flyer)
19/10/21	Information sent to Hospital Trust Membership Scheme Offices with request to share with their membership (Paragraph of text with link to consultation page and flyer)
19/10/21	Information sent to Community Mental Health Providers Membership Scheme Offices with request to share with their membership (Paragraph of text with link to consultation page and flyer)
19/10/21	Emails to Healthwatch colleagues with poster, flyer, suggested text for newsletter, links to CCG social media platforms with request to share via their networks
21/10/21	Letter emailed to Bourne Hall Fertility Clinic to formally invite response to Consultation
21/10/21	Letter emailed to Healthwatch Milton Keynes to formally invite response to Consultation
21/10/21	Letter emailed to Healthwatch Luton to formally invite response to Consultation

Engagement Log	
Date	**Activity**
21/10/21	Letter emailed to Healthwatch Bedford Borough to formally invite response to Consultation
21/10/21	Letter emailed to Healthwatch Central Bedfordshire to formally invite response to Consultation
21/10/21	Public engagement session held online
22/10/21	Letter emailed to Bedford Borough OSC to formally invite response to Consultation
22/10/21	Letter emailed to Central Bedfordshire OSC to formally invite response to Consultation
22/10/21	Letter emailed to Milton Keynes Council OSC to formally invite response to Consultation
22/10/21	Letter emailed to Luton Council OSC to formally invite response to Consultation
22/10/21	Letter emailed to Fertility Network UK to formally invite response to Consultation
22/10/21	Letter emailed to Coeliac UK to formally invite response to Consultation
22/10/21	Letter emailed to British Specialist Nutrition Association Ltd (BSNA Ltd) to formally invite response to Consultation
22/10/21	Letter emailed to British Dietetic Association (BDA) to formally invite response to Consultation
22/10/21	Email sent to elected councillors in Bedford Borough, Central Bedfordshire, Luton and Milton Keynes informing them of the consultation and request to share and promote with their parishioners (attached poster, flyer, suggested text for newsletter, links to CCG social media platforms).
22/10/21	Emails to Town and Parish Clerks across Bedfordshire and Milton Keynes informing them of the consultation and request to share and promote with their parishioners (attached poster, flyer, suggested text for newsletter, links to CCG social media platforms). Email also advised that posters were being send via post.
22/10/21	Information promoting consultation uploaded to waiting-room screens in GP practices across BLMK
22/10/21	Information promoting consultation uploaded to screen-savers for BLMK staff
22/10/21	Information sent for cascading to Covid Champions across BLMK (Paragraph of text with link to consultation page, poster and flyer)
22/10/21	Email to faith groups informing them of the consultation and request to share with networks (attached poster, flyer, suggested text for newsletter, links to CCG social media platforms)
22/10/21	Information sent to Equality and Diversity leads at LAs, Gypsy and Traveller liaison officers at LAs and groups with request to share with via their networks - (attached poster, flyer, suggested text for newsletter, links to CCG social media platforms)
22/10/21	Information sent to voluntary organisations and groups with request to share with via their networks - (attached poster, flyer, suggested text for newsletter, links to CCG social media platforms)
25/10/21	Letter emailed to Milton Keynes and Northamptonshire LPC to formally invite response to Consultation
25/10/21	Letter emailed to Bedfordshire LPC to formally invite response to Consultation
25/10/21	Email to Bucks Coeliac UK Group asking to share consultation information with the network
26/10/21	Email to fertility support group administrator, informing them of the consultation and request to share with networks (attached poster, flyer, suggested text for newsletter, links to CCG social media platforms)

Engagement Log	
Date	**Activity**
26/10/21	Email to LA colleagues who are the conduit for cascading information to Childrens Centres, informing them of the consultation and request to share with networks (attached poster, flyer, suggested text for newsletter, links to CCG social media platforms)
26/10/21	Email to members of the BLMK ICS Communications Collaborative with information about the consultation and request to share with staff and local residents via their networks and communication channels. (Attached poster, flyer, suggested text for newsletter, links to CCG social media platforms, social media tile)
26/10/21	Email to colleague at BRCC who acts as a conduit for cascading information to Community centres and village halls in Central Bedfordshire, informing them of the consultation and request to share with centres and halls (attached poster, flyer, suggested text for newsletter, links to CCG social media platforms)
26/10/21	Information sent to colleagues in public health for cascading to members of the L.A. Faith Leader groups across BLMK (Paragraph of text with link to consultation page, poster and flyer)
26/10/21	Email to BLMK CCG Governing Body advising consultation had been launched, included link to consultation
26/10/21	Email sent to MPs for the BLMK area informing them of consultation, with Case for Change document, poster and flyer and link to information on website
26/10/21	Email to local organisations asking for information to be included in community newsletter (paragraph of text with links etc)
26/10/21	Email received from Milton Keynes Healthwatch advising they will add the Policy Alignment consultation to the agenda of their next Board meeting
26/10/21	Response received from the Chief Officer of Northamptonshire and Milton Keynes LPC advising that they will consider their response to the Policy alignment consultation in their November meeting.
27/10/21	Response received from the Democracy and Scrutiny Officer at Luton Council advising that no formal response will be submitted by the Luton Health and Social Care Review Group, as the proposals have been scrutinised at a review group meeting. Members will respond individually if they wish to do so.
27/10/21	Confirmation received from CBC Communications, Knowledge and Insight Team that social media posts have been shared (and will schedule a couple of future posts) and information will be included in staff newsletter w/c 01/11/21
27/10/21	Email to Nutrition and Dietetics service (provide support for people with learning disabilities) informing them of the consultation and request to share with networks (attached poster, flyer, suggested text for newsletter, links to CCG social media platforms, easy read docs)
27/10/21	Information included in staff bulletin encouraging participation and sharing social media posts /promoting consultation via networks
27/10/21	Information about consultation included in BLMK CCG staff bulletin
27/10/21	Email to voluntary groups and organisations informing them of the consultation and request to share with networks (attached poster, flyer, suggested text for newsletter, links to CCG social media platforms)
27/10/21	Information sent to youth engagement leads at LAs with request to share with Young people - (attached poster, flyer, suggested text for newsletter, links to CCG social media platforms)

Engagement Log	
Date	**Activity**
28/10/21	Email to Q:Alliance (Milton Keynes) informing them of the consultation and request to share with networks (attached poster, flyer, suggested text for newsletter, links to CCG social media platforms)
28/10/21	Bedford Borough Council circulated information about the consultation with poster, flyer, suggested text for newsletter, links to CCG social media platforms to Faith leaders group
28/10/21	Information about consultation included in CVS newsletter https://mailchi.mp/cvsbeds/cvsupdate28102021
28/10/21	Email to Engagement Team at Luton Council to request information about consultation be included in November edition of new community newsletter
28/10/21	Information included in Healthwatch Central Bedfordshire's Bits & Bytes newsletter issued 28/10/21 and home page of website
28/10/21	Confirmation received that information would be included in November edition of Luton Council's Voluntary and Community newsletter
1/11/21	Information about consultation included in Bedford Borough Council's 'Consulting Bedford' newsletter / email
2/11/21	Email response received from British Dietetic Association (BDA) advising they have a national statement on gluten free food on prescription and that they have shared the invitation to response to the consultation with local BDA groups.
2/11/21	Printed poster and covering letter sent 2nd class to all Town and Parish clerks in Bedford Borough, Central Bedfordshire and Milton Keynes to advise of consultation, request to display poster on notice board in public area, and to lookout for email with further information about the consultation. Further plea to share the messages with local residents via their channels.
3/11/21	Public health colleagues at Bedford Borough Council shared the information sent to them on 26/10/21 with faith leaders in Bedford Borough
3/11/21	Public health colleagues at Bedford Borough Council shared the information sent to them on 26/10/21 with Covid Champions in Bedford Borough
4/11/21	Information about consultation included in VOCypf newsletter / email
4/11/21	Information about consultation included in Healthwatch Milton Keynes newsletter / email
8/11/21	Paper Submitted to Central Bedfordshire Overview and Scrutiny Committee for presentation at their 22 November 2021 meeting.
9/11/21	Telephone conversation with Paula at Bedfordshire Chamber of Commerce who agreed to include information about consultation in next newsletter (24/11/21) distributed to 14k contacts in Bedfordshire.
9/11/21	Telephone conversation and Email to Mandy at Milton Keynes Chamber of Commerce with request to share with their members in Milton Keynes.
12/11/21 to 18/11/21	Covering letter, printed posters and consultation documents sent to all GP practices and branch surgeries across BLMK
16/11/21	Printed posters, A5 flyers and consultation documents delivered to Healthwatch Central Bedfordshire
17/11/21	Video featuring lay member for Patient and Public Engagement encouraging residents to take part in consultation and details of drop-in sessions added to homepage of BLMK CCG website and included in social media campaign
18/11/21	Covering letter, printed posters, A5 flyers and consultation documents sent to all children's centres across BLMK

Engagement Log	
Date	**Activity**
19/11/21	Printed posters, A5 flyers and consultation documents delivered to Luton Central Library for distribution to all 5 libraries in Luton
19/11/21	Printed posters, A5 flyers and consultation documents sent to Milton Keynes Central Library for distribution with other libraries in Milton Keynes
19/11/21	Printed posters, A5 flyers delivered to Healthwatch Luton
19/11/21	Consultation documents given to staff attending ELFT training event in Luton
19/11/21	Public drop-in session held at Tokko, Luton Town Centre providing opportunity to ask the clinical leads and commissioners questions about the consultation
19/11/21	Printed posters, A5 flyers and consultation documents provided for Healthwatch Bedford Borough
20/11/21	Healthwatch Bedford Borough and Healthwatch Central Bedfordshire shared information about consultation at their engagement session with Deaf community
22/11/21	Printed posters and A5 flyers sent to Bedford Central Library for distribution with other libraries in Bedford Borough
22/11/21	Printed posters and A5 flyers sent to Flitwick Library for distribution with other libraries in Central Bedfordshire
23/11/21	Consultation documents sent to Healthwatch Luton
23/11/21	Printed posters, A5 flyers and consultation documents posted to Healthwatch Milton Keynes
23/11/21	Telephone conversation with member of the public who wished to share their patient experience
25/11/21	Email to housing associations asking for their support to share the consultation with their resident groups and tenants, email included suggested text for email/newsletter and link to a Facebook and Twitter post with request to share
26/11/21	Facebook and Instagram advertising published to run from 26 Nov - 16 Dec 2021 across BLMK
30/11/21	Public engagement session held online
1/12/21	Video featuring Clinical lead and Governing Body member encouraging residents to take part in consultation added to homepage of BLMK CCG website and included in social media campaign
2/12/21	Reminder email sent to Maternity Voice Partnerships (MVPs) advising last few weeks of consultation, asking them for continued support to promote consultation via networks. Email included link to a Facebook and Twitter post with a short video of clinical lead encouraging residents to take part in consultation and suggested text for newsletters, bulletins etc.
2/12/21	Reminder email sent to local fertility centres advising last few weeks of consultation, asking them for continued support to promote consultation via networks. Email included link to a Facebook and Twitter post with a short video of clinical lead encouraging residents to take part in consultation and suggested text for newsletters, bulletins etc.
2/12/21	Reminder email sent to womens' groups advising last few weeks of consultation, asking them for continued support to promote consultation via networks. Email included link to a Facebook and Twitter post with a short video of clinical lead encouraging residents to take part in consultation and suggested text for newsletters, bulletins etc.

Engagement Log	
Date	**Activity**
2/12/21	Reminder email sent to LGBTQ groups advising last few weeks of consultation, asking them for continued support to promote consultation via networks. Email included link to a Facebook and Twitter post with a short video of clinical lead encouraging residents to take part in consultation and suggested text for newsletters, bulletins etc.
2/12/21	Reminder email sent to local support organisations advising last few weeks of consultation, asking them for continued support to promote consultation via networks. Email included link to a Facebook and Twitter post with a short video of clinical lead encouraging residents to take part in consultation and suggested text for newsletters, bulletins etc.
2/12/21	Reminder email sent to local food banks advising last few weeks of consultation, asking them for continued support to promote consultation via networks. Email included link to a Facebook and Twitter post with a short video of clinical lead encouraging residents to take part in consultation and suggested text for newsletters, bulletins etc.
2/12/21	Reminder email sent to community centres advising last few weeks of consultation, asking them for continued support to promote consultation via networks. Email included link to a Facebook and Twitter post with a short video of clinical lead encouraging residents to take part in consultation and suggested text for newsletters, bulletins etc.
2/12/21	Reminder email sent to local foodbanks advising last few weeks of consultation, asking them for continued support to promote consultation via networks. Email included link to a Facebook and Twitter post with a short video of clinical lead encouraging residents to take part in consultation and suggested text for newsletters, bulletins etc.
2/12/21	Reminder email sent to Hospital Trust Membership Scheme Officers advising last few weeks of consultation, asking them for continued support to promote consultation via networks. Email included link to a Facebook and Twitter post with a short video of clinical lead encouraging residents to take part in consultation and suggested text for newsletters, bulletins etc.
2/12/21	Reminder email sent to local Healthwatch organisations advising last few weeks of consultation, asking them for continued support to promote consultation via networks. Email included link to a Facebook and Twitter post with a short video of clinical lead encouraging residents to take part in consultation and suggested text for newsletters, bulletins etc.
2/12/21	Reminder email sent to Bedford Borough, Central Bedfordshire, Luton and Milton Keynes elected councillors advising last few weeks of consultation, asking them for continued support to promote consultation with their constituents. Email included link to a Facebook and Twitter post with a short video of clinical lead encouraging residents to take part in consultation and suggested text for newsletters, bulletins etc.
2/12/21	Reminder email sent to Town and Parish clerks in Bedford Borough, Central Bedford and Milton Keynes, advising last few weeks of consultation, asking them for continued support to promote consultation via networks. Email included link to a Facebook and Twitter post with a short video of clinical lead encouraging residents to take part in consultation and suggested text for newsletters, bulletins etc.

Engagement Log	
Date	**Activity**
2/12/21	Reminder email sent to Covid Champions across BLMK advising last few weeks of consultation, asking them for continued support to promote consultation via networks. Email included link to a Facebook and Twitter post with a short video of clinical lead encouraging residents to take part in consultation and suggested text for newsletters, bulletins etc.
2/12/21	Reminder email sent faith groups across BLMK Scheme advising last few weeks of consultation, asking them for continued support to promote consultation via networks. Email included link to a Facebook and Twitter post with a short video of clinical lead encouraging residents to take part in consultation and suggested text for newsletters, bulletins etc.
2/12/21	Reminder email sent to Equality and Diversity leads at LAs, Gypsy and Traveller liaison officers at LAs and groups advising last few weeks of consultation, asking them for continued support to promote consultation via networks. Email included link to a Facebook and Twitter post with a short video of clinical lead encouraging residents to take part in consultation and suggested text for newsletters, bulletins etc.
2/12/21	Reminder email sent to voluntary organisations advising last few weeks of consultation, asking them for continued support to promote consultation via networks. Email included link to a Facebook and Twitter post with a short video of clinical lead encouraging residents to take part in consultation and suggested text for newsletters, bulletins etc.
2/12/21	Reminder email sent to members of the BLMK ICS Communications Collaborative advising last few weeks of consultation, asking them for continued support to promote consultation via networks. Email included link to a Facebook and Twitter post with a short video of clinical lead encouraging residents to take part in consultation and suggested text for newsletters, bulletins etc.
2/12/21	Reminder email sent to colleague at Bedfordshire Rural Communities Charity (BRCC) advising last few weeks of consultation, asking them for continued support to promote consultation via networks. Email included link to a Facebook and Twitter post with a short video of clinical lead encouraging residents to take part in consultation and suggested text for newsletters, bulletins etc.
2/12/21	Reminder email sent to colleagues in public health for cascading to members of the Faith Leaders Groups across BLMK advising last few weeks of consultation, asking them for continued support to promote consultation via networks. Email included link to a Facebook and Twitter post with a short video of clinical lead encouraging residents to take part in consultation and suggested text for newsletters, bulletins etc.
2/12/21	Reminder email sent to voluntary groups and organisations advising last few weeks of consultation, asking them for continued support to promote consultation via networks. Email included link to a Facebook and Twitter post with a short video of clinical lead encouraging residents to take part in consultation and suggested text for newsletters, bulletins etc.
2/12/21	Reminder email sent to Youth Engagement leads advising last few weeks of consultation, asking them for continued support to promote consultation via networks. Email included link to a Facebook and Twitter post with a short video of clinical lead encouraging residents to take part in consultation and suggested text for newsletters, bulletins etc.

Engagement Log	
Date	**Activity**
2/12/21	Reminder email sent to Bedfordshire and Milton Keynes Chamber of Commerce advising last few weeks of consultation, asking them for continued support to promote consultation via networks. Email included link to a Facebook and Twitter post with a short video of clinical lead encouraging residents to take part in consultation and suggested text for newsletters, bulletins etc.
6/12/21	Reminder email sent to community pharmacies in BLMK, asking them for continued support to promote consultation via networks. Email included link to a Facebook and Twitter post with a short video of clinical lead encouraging residents to take part in consultation and suggested text for newsletters, bulletins etc.
7/12/21	Reminder included in primary care news bulletin shared with GP practices across BLMK
7/12/21	Reminder email sent to practice managers advising last few weeks of consultation, asking them for continued support to promote consultation via networks. Email included link to a Facebook and Twitter post with a short video of clinical lead encouraging residents to take part in consultation and suggested text for newsletters, bulletins etc.

Appendix 5

BLMK CCG Policy alignment consultation
Stakeholders

Stakeholder groups and cohorts
Groups and organisations with potential interest in fertility services
Bourne Hall Fertility Clinic
L&D Fertility Centre
Fertility Clinics
Womens groups
Fertility Network UK
National Fertility Society
Fertility Network UK (Bedfordshire)
L&D Fertility Centre
Bedford Maternity Voices
Luton & Dunstable Maternity Voices
Maternity:MK Maternity Voices Partnership
CARE Fertility Milton Keynes
Fertility in Community Luton
Milton Keynes Fertility Satellite Clinic - overseen by The Fertility Partnership (TFP)
The Ultrasound Clinic, Bedfordshire
Infertility Support group (via net mums)
Net mums
Bedford Bandhan
Shanthona Women's Group (Luton)
Groups and organisations with potential interest in gluten-free food prescribing
Coeliac UK
Coeliac UK (local support branches)
British Dietary Association (BDA)
Association of UK Dieticians
British Specialist Nutrition Association (BSNA)
BDA Association of UK Dieticians
Glutarama
Stanley's Treats
Nutrition and dietetic service (Adults with a learning disability)
Groups and organisations with potential interest in Pharmacy First Minor Ailment Scheme
LPC Bedfordshire
LPC Northamptonshire and Milton Keynes
Groups and organisations support LGBTQ community
Q:alliance
The Beaumont Society
Q:alliance (Milton Keynes)
QYouth Bedford
Q:Youth MK
OK2B (LGBT Youth Project)
ELFT LGBTQ+ steering group
BEING ME' peer support group
LGBTQ+ Friends (peer support group)
Groups and organisations who may have contact to people on low incomes
Financial advice organisations (Credit Unions, CABs, Salvation Army etc)
Childrens' Centres
Community centres
Housing Associations
Voluntary organisations
Homeless Charities
Bedfordshire Foodbanks
Luton Foodbank
Dunstable Foodbank
Milton Keynes Food Bank
Bedford Credit Union
Money Matters Credit Union
M for Money
Swan Community Bank
MK money lifeline
The Need Project

Stakeholders

Salvation Army
Children's centres in Milton Keynes
Childrens Centres In Central Bedfordshire
Children's centres in Bedford Borough
Childrens centres in Luton
Amicus Trust
Barton and Royle Homes
Emmaus Village Carlton
IMPAKT Housing & Support
King's Arms Project (Kings Arms Trust)
NOAH Enterprise
The Harpur Trust
Level Trust
Stonewater Housing
SMART - Bedford
Community centres in Milton Keynes
Community Centres In Central Bedfordshire
Community centres in Bedford Borough
Community centres in Luton
Patients and Residents
Patient Participation Groups (PPGs) across BLMK
Foundation Trust membership schemes (Bedfordshire Hospitals (BHT L&D), Milton Keynes Hospital, ELFT etc)
Town and Parish Councils (Bedford Borough, Central Bedfordshire, Luton and Milton Keynes)
Community groups across BLMK
Faith groups
Disability Groups
Young people
Ethnic minority groups
Milton Keynes Hospital members
ELFT membership scheme
CNWL membership scheme
Town and Parish Councils in Bedford Borough
Town and Parish Councils in Central Bedfordshire
Town and Parish Councils in Milton Keynes
Town and Parish Councils in Luton
Covid Champions Bedford Borough
Covid Champions Central Bedfordshire
Covid Champions Luton
Covid Champions Milton Keynes
MK Community Foundation
Bedford Borough faith leaders group
Luton faith leaders group
Milton Keynes faith leaders
Luton Council of Faiths
Bedfordshire Council of Faiths
Milton Keynes Council of Faiths
Interfaith MK
Milton Keynes Islamic Arts, Heritage and Culture
Milton Keynes Muslim Association
Milton Keynes Islamic Society
Milton Keynes Christian Foundation
Retired Caribbean nurses
Active Luton
Autism Bedfordshire
Access Bedford
Access Ambassadors CIC
Deaf Support MK
Disability Resource Centre
Milton Keynes Centre for Integrated Living
Sight Concern Bedfordshire
Bucks vision
Bedford and District Audio News
Carers in Bedfordshire
Carers MK
Carers Central

Stakeholders

Nutrition and dietic service
Youth Engagement Team - Bedford Borough Council
Youth Engagement Team - Central Bedfordshire Council
Youth Engagement Team - Luton Council
Youth Engagement Team - Milton Keynes Council
Equality and Diversity Lead - Bedford Borough Council
Equality and Diversity Lead - Central Bedfordshire Council
Equality and Diversity Lead - Luton Council
Equality and Diversity Lead - Milton Keynes Council
ACCM (Agency for Culture and Change Management UK)
Irish Forum
Luton Roma Trust
Gypsy, Roma and Traveller site liaison officers (at LAs)
Staff from the organisations that form BLMK Integrated Care System
BLMK Clinical Commissioning Group
Bedford Borough Council
Central Bedfordshire Council
Milton Keynes Council
Luton Borough Council
Bedfordshire Hospitals NHS Foundation Trust
Milton Keynes University Hospital NHS Foundation Trust
Cambridgeshire Community Services NHS Trust
Central and North West London NHS Foundation Trust
East London NHS Foundation Trust
East of England Ambulance Service NHS Trust
South Central Ambulance Service NHS Foundation Trust
Key stakeholders and organisations
Healthwatch Bedford Borough
Healthwatch Central Bedfordshire
Healthwatch Luton
Healthwatch Milton Keynes
Community Action Milton Keynes
Community Voluntary Service (CVS) Bedfordshire
Community Action Bedfordshire (Central Beds)
Carers in Bedfordshire
Carers MK
Carers Central
Age Concern Luton
Age UK Bedfordshire
Age UK Milton Keynes
Guild House
BLEVEC
Macmillan
Consultation team - Central Bedfordshire Council
Consultation team - Luton Council
Consultation team - Bedford Borough Council
Consultation team - Milton Keynes Council
BPHA
Bedford Citizens Housing Association
Hanover Housing Association
Stonewater (prev Jephson HA)
Aldwyck
Grand Union Housing Group
Home Housing Association (08451552305)
Hastoe Housing Association
Hanover Housing Association (Anchor)
Guinness Partnership
Squared
Healthcare Professionals
Local Pharmaceutical Committees (LPCs)
Local Medical Committees (LMCs)
Pharmacies across BLMK
Nutrition and Dietetic professionals (via hospitals and community teams)

Stakeholders

GPs and nurses across BLMK
Elected members, MPs and committees and boards
Elected members (Bedford Borough, Central Bedfordshire, Luton and Milton Keynes)
MPs across Bedfordshire, Luton and Milton Keynes
Overview and Scrutiny Boards (Bedford Borough, Central Bedfordshire, Luton and Milton Keynes)
Newsletters
Local authority e-zines and bulletins
Healthwatch newsletters
Vol orgs (CVS, Age UK, Carers in Beds, BRCC etc)
Community and village newsletters
CVS - Beds and Luton
VOCypf
BRCC
Community Action Milton Keynes
Carers in Bedfordshire
Luton Voluntary and Community monthly newsletter
Milton Keynes Chamber of Commerce
Bedfordshire Chamber of Commerce

Appendix 6

BLMK CCG, Policy Alignment Public Consultation

Social media log

	Twitter								Facebook								Instagram							
Date	Post	Image / Video	Impressions	Video watched	Likes	Retweets	Retweet/Quote tweet by		Date	Post	Image / Video	Reach	Video watched	Engagement	Likes	Shares	Post shared by		Date	Post	Image / Video	Reach	Video Views	Impressions	Likes	
12/10/2021	Share your opinions and get involved with our consultation on policy alignments. We want your views on prescribing gluten-free foods, Milton Keynes Pharmacy First, and fertility services. Click on the link to take part! #BLMKWhatsYourView	Image - BLMK ICS logo	345		0	0			12/10/21	Share your opinions and get involved with our consultation on policy alignments. We want your views on prescribing gluten-free foods, Milton Keynes Pharmacy First, and fertility services. Click on the link to take part! #BLMKWhatsYourView	Image - Policy consultation				2	3	Healthwatch Bedford Borough 2 Anonymous		14/10/2021	Share your opinions and get involved with our consultation on policy alignments. We want your views on prescribing gluten-free foods, Milton Keynes Pharmacy First, and fertility services. Click on the link to take part! #BLMKWhatsYourView blmkccg.nhs.uk/PolicyConsultation	Public Consultation Image	81		88	2		
15/10/2021	Have a question about our Consultation on aligning policies across BLMK? Come along to our first online engagement session Thursday 21 October, 6:00 - 7:30pm. You must book in advance. Information on the consultation page (https://t.co/NIRrcjNUhR #BLMKWhatsYourView" / Twitter	Image - BLMK ICS logo	171		0	0			15/10/21	Have a question about our Consultation on aligning policies across BLMK? Come along to our first online engagement session Thursday 21 October, 6:00 - 7:30pm. You must book in advance. Information on the consultation page (http://ow.ly/DBdY50GrXq8 #BLMKWhatsYourView	Image - BLMK ICS logo	174		3	0	0			18/10/2021	Have your say! Join in our BLMK Policy alignment consultation and share your view! https://eu.surveymonkey.com/r/BLMK-PolicyAlignment #NHS #Gluten-free #Pharmacy #Fertility #BLMKWhatsYourView	Tell us your Views	60		60	1		
15/10/2021	(4) NHS Bedfordshire, Luton and Milton Keynes CCG ♡ on Twitter: "Have a question about our Consultation on aligning policies across BLMK? Come along to our first online engagement session Thursday 21 October, 6:00 - 7:30pm. You must book in advance. Information on the consultation page (https://t.co/NIRrcjNUhR #BLMKWhatsYourView" / Twitter	Image - BLMK ICS logo	173		0	0			15/10/21	Take part and share your views on aligning policies so there is equal access to the services we commission within your local area! https://eu.surveymonkey.com/r/BLMK-PolicyAlignment #BLMKWhatsYourView		137		2	0	0			19/10/2021	Share your opinions and get involved with our consultation on policy alignments. We want your views on prescribing gluten-free foods, Milton Keynes Pharmacy First, and fertility services. Click on the link to take part! #BLMKWhatsYourView blmkccg.nhs.uk/PolicyConsultation	Public Consultation Image	68		70	1		
16/10/2021	(4) NHS Bedfordshire, Luton and Milton Keynes CCG ♡ on Twitter: "This weekend, get involved with our consultation on policy alignments. We want your views on prescribing gluten-free foods, Milton Keynes Pharmacy First, and fertility services. Click on the link to take part. https://t.co/XJcl8ah1rT! #BLMKWhatsYourView" / Twitter	Image – public consultation	256		0	0			16/10/21	This weekend, get involved with our consultation on policy alignments. We want your views on prescribing gluten-free foods, Milton Keynes Pharmacy First, and fertility services. Click on the link to take part. https://eu.surveymonkey.com/r/BLMK-PolicyAlignment! #BLMKWhatsYourView	Image – public consultation	140		0	0	0			20/10/2021	Have your say! Join in our BLMK Policy alignment consultation and share your view! #NHS #Gluten-free #Pharmacy #Fertility #BLMKWhatsYourView www.blmkccg.nhs.uk/PolicyConsultation	Public Consultation Image	72		74	1		
18/10/2021	(4) NHS Bedfordshire, Luton and Milton Keynes CCG ♡ on Twitter: "Have a question about our Consultation on aligning policies across BLMK? Come along to our first online engagement session Thursday 21 October, 6:00 - 7:30pm. You must book in advance. (https://t.co/usoJZ0rycp #BLMKWhatsYourView" / Twitter	Image – Drop-in sessions	191						18/10/21	Have a question about our Consultation on aligning policies across BLMK? Come along to our first online engagement session Thursday 21 October, 6:00 - 7:30pm. You must book in advance. Information on the consultation page www.blmkccg.nhs.uk/PolicyConsultation	Image – Drop-in sessions					1		23/10/2021	Have your say! Join in our BLMK Policy alignment consultation and share your view! #NHS #Gluten-free #Pharmacy #Fertility #BLMKWhatsYourView	Public Consultation Image	71		76	1		
18/10/2021	(4) NHS Bedfordsh+F2:H7ire, Luton and Milton Keynes CCG ♡ on Twitter: "Have your say! Join in our BLMK Policy alignment consultation and share your view! #NHS #Gluten-free #Pharmacy #Fertility #BLMKWhatsYourView https://t.co/3928YKf8IZ https://t.co/aryEFM7Tsu" / Twitter	Image – Tell us your views	210		0	0			24/10/21	This weekend share your views on Fertility Services, Gluten-Free Prescribing and Pharmacy First Minor Ailment Scheme by clicking on the link and taking part in the BLMK policy alignment consultation #BLMKWhatsYourView blmkccg.nhs.uk/PolicyConsultation	Image – Tell us your views	630		9	0	3	Healthwatch Bedford Borough Barton-le-Clay Parish Council Anonymous	24/10/2021	This weekend share your views on Fertility Services, Gluten-Free Prescribing and Pharmacy First Minor Ailment Scheme by clicking on the link and taking part in the BLMK policy alignment consultation #BLMKWhatsYourView blmkccg.nhs.uk/PolicyConsultation	Public Consultation Image	59		60	1		
20/10/2021	NHS Bedfordshire, Luton and Milton Keynes CCG ♡ on Twitter: "Have your say! Join in our BLMK Policy alignment consultation and share your view! #NHS #Gluten-free #Pharmacy #Fertility #BLMKWhatsYourView https://t.co/ruJpB5qH9R https://t.co/yF0eqQWKnw" / Twitter	Image – Tell us your views	316		1	0			25/10/21	We want your views on gluten-free food, over the counter medicines and fertility services... Take part in our policy alignment consultation. www.blmkccg.nhs.uk/PolicyConsultation #BLMKWhatsYourView	Image – public consultation	1895		58	1	6	Campbell Park Parish Council News Ampthill Town Council Woburn Sands Town Council Clifton Parish Council 2 Anonymous	29/10/2021	We have #EasyRead explaining what our policies are about and what we want to do about it. What do you think about our ideas? Information on our consultation page www.blmk.nhs.uk/PolicyConsultation #BLMKWhatsYourView	Easy Read Image	40		41	1		
22/10/2021	NHS Bedfordshire, Luton and Milton Keynes CCG ♡ (@BLMK_CCG) / Twitter	Image - BLMK ICS logo							27/10/2021	Have your say! Join in our BLMK Policy alignment consultation and share your view! www.blmkccg.nhs.uk/PolicyConsultation #NHS #Gluten-free #Pharmacy #Fertility #BLMKWhatsYourView	Image – Tell us your views	2127		12	0	3	Central Bedfordshire Council Time2Connect Houghton Regis 1 Anonymous	03/11/2021	We want your views on prescribing gluten-free food, Milton Keynes Pharmacy First and Fertility Services... Take part in our policy alignment consultation. #BLMKWhatsYourView www.blmkccg.nhs.uk/PolicyConsultation	Public Consultation Image	42		42	1		
25/10/2021	NHS Bedfordshire, Luton and Milton Keynes CCG ♡ on Twitter: "We want your views on gluten-free food, over the counter medicines and fertility services... Take part in our policy alignment consultation. https://t.co/3928YKf8IZ	Image – Tell us your views	257		0	0			29/10/2021	We have #EasyRead explaining what our policies are about and what we want to do about it. What do you think about our ideas? Information on our consultation page www.blmk.nhs.uk/PolicyConsultation #BLMKWhatsYourView	Image - Easy read	210		1	0	0		05/11/2021	This weekend share your views on Fertility Services, Gluten-Free Prescribing and Pharmacy First Minor Ailment Scheme by clicking on the link and taking part in the BLMK policy alignment consultation #BLMKWhatsYourView	Public Consultation Image	47		47	1		
27/10/2021	NHS Bedfordshire, Luton and Milton Keynes CCG ♡ on Twitter: "Have your say! Join in our BLMK Policy alignment consultation and share your view! https://t.co/3928YKf8IZ #NHS #Gluten-free #Pharmacy #Fertility	Image – Tell us your views							29/10/2021	This weekend, get involved with our consultation on policy alignments. We want your views on prescribing gluten-free foods, Milton Keynes Pharmacy First, and fertility services. Click on the link to take part!	Image – Tell us your views	208		1	0	0		08/11/2021	Have your say! Join in our BLMK Policy alignment consultation and share your view! #NHS #Gluten-free #Pharmacy #Fertility #BLMKWhatsYourView www.blmkccg.nhs.uk/PolicyConsultation	Public Consultation Image	53		59	2		

Social media log

Twitter								Facebook								Instagram							
Date	Post	Image / Video	Impressions	Video watched	Likes	Retweets	Retweet/Quote tweet by	Date	Post	Image / Video	Reach	Video watched	Engagement	Likes	Shares	Post shared by	Date	Post	Image / Video	Reach	Video Views	Impressions	Likes	
29/10/2021	(1) NHS Bedfordshire, Luton and Milton Keynes CCG ♡ on Twitter: "We have #EasyRead explaining what our policies are about and what we want to do about it. What do you think about our ideas? Information on our consultation page https://t.co/EZBPGdlr28 #BLMKWhatsYourView https://t.co/WDRiiLLArP" / Twitter	Image - Easy read	202		0	0		3/11/2021	We want your views on prescribing gluten-free food, Milton Keynes Pharmacy First and Fertility Services... Take part in our policy alignment consultation. #BLMKWhatsYourView www.blmkccg.nhs.uk/PolicyConsultation	Image – Tell us your views	196		1	0	0		10/11/2021	Have a question about our consultation? Call into our drop-in session at Tokko Youth Space, 7 Gordon Street, Luton on Fri 19 Nov, 10:30-12. Information on our consultation page www.blmkccg.nhs.uk/PolicyConsultation #BLMKWhatsYourView	Public Consultation Image	51		51	2		
29/10/2021	(2) NHS Bedfordshire, Luton and Milton Keynes CCG ♡ on Twitter: "This weekend, get involved with our consultation on policy alignments. We want your views on prescribing gluten-free foods, Milton Keynes Pharmacy First, and fertility services. Click on the link to take part! https://t.co/3928YKf8IZ #BLMKWhatsYourView https://t.co/WpKMKCfdok" / Twitter	Image – Tell us your views	184		0	0		05/11/2021	This weekend share your views on Fertility Services, Gluten-Free Prescribing and Pharmacy First Minor Ailment Scheme by clicking on the link and taking part in the BLMK policy alignment consultation #BLMKWhatsYourView www.blmkccg.nhs.uk/PolicyConsultation	Image – Tell us your views	441		9	0	2	Healthwatch Bedford Borough Anonymous	11/11/2021	Have your say about healthcare policies in BLMK www.blmkccg.nhs.uk/PolicyConsultation #BLMKWhatsYourView	Public Consultation Image	39		39	1		
01/11/2021	NHS Bedfordshire, Luton and Milton Keynes CCG ♡ on Twitter: "Have your say! Join in our BLMK Policy alignment consultation and share your view! https://t.co/3928YKf8IZ #NHS #Gluten-free #Pharmacy #Fertility #BLMKWhatsYourView https://t.co/SuJKUV2FOV" / Twitter	Image – Tell us your views	956			3	@LutonCouncil @BFSTownCouncil Anon	10/11/2021	Have a question about our consultation? Call into our drop-in session at Tokko Youth Space, 7 Gordon Street, Luton on Fri 19 Nov, 10:30-12. Information on our consultation page www.blmkccg.nhs.uk/PolicyConsultation #BLMKWhatsYourView	Image – Drop-in sessions	231		3	0	0		12/11/2021	We're consulting on making our policies the same across Bedfordshire, Luton and Milton Keynes. Have your say about future services by taking part www.blmkccg.nhs.uk/PolicyConsultation #BLMKWhatsYourView	Public Consultation Image	46		47	2		
03/11/2021	NHS Bedfordshire, Luton and Milton Keynes CCG ♡ on Twitter: "We want your views on prescribing gluten-free food, Milton Keynes Pharmacy First and Fertility Services... Take part in our policy alignment consultation. #BLMKWhatsYourView https://t.co/3928YKf8IZ https://t.co/RJSXKYHLD5" / Twitter	Image – Tell us your views	226		1			11/11/2021	Have your say about healthcare policies in BLMK www.blmkccg.nhs.uk/PolicyConsultation #BLMKWhatsYourView	Image – Tell us your views	506		6	0	1	David Foord	15/11/2021	Have a question about our consultation? Call into our drop-in session at Tokko Youth Space, 7 Gordon Street, Luton on Fri 19 Nov, 10:30-12 Information on our consultation page www.blmk.nhs.uk/PolicyConsultation #BLMKWhatsYourView	Public Consultation Image	60		61	2		
05/11/2021	NHS Bedfordshire, Luton and Milton Keynes CCG ♡ on Twitter: "This weekend share your views on Fertility Services, Gluten-Free Prescribing and Pharmacy First Minor Ailment Scheme by clicking on the link and taking part in the BLMK policy alignment consultation #BLMKWhatsYourView https://t.co/3928YKf8IZ	Image – Tell us your views	214		1	0		12/11/2021	We're consulting on making our policies the same across Bedfordshire, Luton and Milton Keynes. Have your say about future services by taking part www.blmkccg.nhs.uk/PolicyConsultation #BLMKWhatsYourView	Image – Tell us your views	190		0	0	0		16/11/2021	We're consulting on making our policies the same across Bedfordshire, Luton and Milton Keynes. Have your say about future services by taking part www.blmkccg.nhs.uk/PolicyConsultation #BLMKWhatsYourView	Public Consultation Image	38		40	2		
08/11/2021	NHS Bedfordshire, Luton and Milton Keynes CCG ♡ on Twitter: "Have your say! Join in our BLMK Policy alignment consultation and share your view! #NHS #Gluten-free #Pharmacy #Fertility #BLMKWhatsYourView https://t.co/3928YKf8IZ https://t.co/OfWKOL625I" / Twitter	Image – Tell us your views	847		0	1	@LutonCouncil	16/11/2021	We're consulting on making our policies the same across Bedfordshire, Luton and Milton Keynes. Have your say about future services by taking part www.blmkccg.nhs.uk/PolicyConsultation #BLMKWhatsYourView	Image – Tell us your views	172		0	0	0		16/11/2021	We're consulting on making our policies the same across Bedfordshire, Luton and Milton Keynes. Have your say about future services by taking part www.blmkccg.nhs.uk/PolicyConsultation #BLMKWhatsYourView	Alison Borett Video	91	50	96	5		
10/11/2021	NHS Bedfordshire, Luton and Milton Keynes CCG ♡ on Twitter: "Have a question about our consultation? Call into our drop-in session at Tokko Youth Space, 7 Gordon Street, Luton on Fri 19 Nov, 10:30-12. Information on our consultation page https://t.co/3928YKf8IZ #BLMKWhatsYourView https://t.co/8IOdDq4R0b" / Twitter	Image – Drop-in sessions	182		0	0		16/11/2021	We're consulting on making our policies the same across Bedfordshire, Luton and Milton Keynes. Have your say about future services by taking part www.blmkccg.nhs.uk/PolicyConsultation #BLMKWhatsYourView	Video - lay member (AB)	1.1k	562	34	6	10	anonymous shares	17/11/2021	We're consulting on making our policies the same across Bedfordshire, Luton and Milton Keynes. Have your say about future services by taking part www.blmkccg.nhs.uk/PolicyConsultation #BLMKWhatsYourView	Alison Borett Video	30	6	31	2		
11/11/2021	NHS Bedfordshire, Luton and Milton Keynes CCG ♡ on Twitter: "Have your say about healthcare policies in BLMK https://t.co/3928YKf8IZ #BLMKWhatsYourView https://t.co/rZYginKotZ" / Twitter	Image – Tell us your views	398		1	2	@HealthwatchBB @DGFoord	17/11/2021	We're consulting on making our policies the same across Bedfordshire, Luton and Milton Keynes. Have your say about future services by taking part www.blmkccg.nhs.uk/PolicyConsultation #BLMKWhatsYourView	Video - lay member (AB)	156	48	2	2	0	0	18/11/2021	Have a question about our consultation? Call into our drop-in session at Tokko Youth Space, 7 Gordon Street, Luton on Fri 19 Nov, 10:30-12 Information on our consultation page www.blmk.nhs.uk/PolicyConsultation #BLMKWhatsYourViewNovember	Public Consultation Image	48		49	1		
12/11/2021	NHS Bedfordshire, Luton and Milton Keynes CCG ♡ on Twitter: "We're consulting on making our policies the same across Bedfordshire, Luton and Milton Keynes. Have your say about future services by taking part https://t.co/3928YKf8IZ #BLMKWhatsYourView https://t.co/RJp8QfbhFw" / Twitter	Image – Tell us your views	729		3	4	@OMGthisisapain @dochawking @BedfordTweets Anonymous	18/11/2021	We're consulting on making our policies the same across Bedfordshire, Luton and Milton Keynes. Have your say about future services by taking part www.blmkccg.nhs.uk/PolicyConsultation #BLMKWhatsYourView	Video - lay member (AB)	158	52	2	1	0	0	19/11/2021	We're consulting on making our policies the same across Bedfordshire, Luton and Milton Keynes. Have your say about future services by taking part www.blmkccg.nhs.uk/PolicyConsultation #BLMKWhatsYourView	video – clinical lead (AB)	42	16	45	1		
15/11/2021	Have a question about our consultation? Call into our drop-in session at Tokko Youth Space, 7 Gordon Street, Luton on Fri 19 Nov, 10:30-12 Information on our consultation page	Image – Drop-in sessions	257		0	0		18/11/2021	Have a question about our consultation? Call into our drop-in session at Tokko Youth Space, 7 Gordon Street, Luton on Fri 19 Nov, 10:30-12 Information on our consultation page	Image – Drop-in sessions	181		1	0	0		19/11/2021	We want your views on prescribing gluten-free food, Milton Keynes Pharmacy First and Fertility Services... Take part in our policy alignment consultation. #BLMKWhatsYourView	Public Consultation Image	71		73	1		

Social media log

Twitter								Facebook									Instagram							
Date	Post	Image / Video	Impressions	Video watched	Likes	Retweets	Retweet/Quote tweet by	Date	Post	Image / Video	Reach	Video watched	Engagement	Likes	Shares	Post shared by	Date	Post	Image / Video	Reach	Video Views	Impressions	Likes	
16/11/2021	We're half-way through collecting your views on prescribing gluten-free food, Milton Keynes Pharmacy First and Fertility Services... Don't forget to take part in our policy alignment consultation. #BLMKWhatsYourView	Image – Tell us your views	293		0	0		19/11/21	We're consulting on making our policies the same across Bedfordshire, Luton and Milton Keynes. Have your say about future services by taking part www.blmkccg.nhs.uk/PolicyConsultation	Video – lay member (AB)	138	36	0	0	0	0	20/11/2021	This weekend share your views on Fertility Services, Gluten-Free Prescribing and Pharmacy First Minor Ailment Scheme by clicking on the link and taking part in the BLMK policy alignment consultation #BLMKWhatsYourView	Public Consultation Image	51		53	1		
18/11/2021	Have a question about our consultation? Call into our drop-in session at Tokko Youth Space, 7 Gordon Street, Luton on Fri 19 Nov, 10:30-12 Information on our consultation page	Video – lay member (AB)	197	46 views	0	0		20/11/2021	This weekend share your views on Fertility Services, Gluten-Free Prescribing and Pharmacy First Minor Ailment Scheme by clicking on the link and taking part in the BLMK	Image – Tell us your views	315		3	1	0		22/11/2021	We're consulting on making our policies the same across Bedfordshire, Luton and Milton Keynes. Have your say about future services by taking part www.blmkccg.nhs.uk/PolicyConsultation	video – clinical lead (AB)	37	7	37	2		
19/11/2021	Have your say about healthcare policies in BLMK www.blmkccg.nhs.uk/PolicyConsultation #BLMKWhatsYourView	Video – lay member (AB)	190	42 views	0	0		22/11/2021	Tomorrow is the last day! Share your opinions and get involved with BLMK consultation on policy alignments. We want your views on gluten-free food, over the counter medicines and fertility services... Click on the link to take part! #BLMKWhatsYourView	Video – lay member (AB)	158	46	1	1	0	0	23/11/2021	We're consulting on making our policies the same across Bedfordshire, Luton and Milton Keynes. Have your say about future services by taking part! www.blmkccg.nhs.uk/PolicyConsultation #BLMKWhatsYourView 7w	Video – clinical lead (SM)	35	14	39	2		
22/11/2021	NHS Bedfordshire, Luton and Milton Keynes CCG ♡ on Twitter: "We're consulting on making our policies the same across Bedfordshire, Luton and Milton Keynes. Have your say about future services by taking part https://t.co/3928YKf8IZ #BLMKWhatsYourView https://t.co/bYA2n4LMfD" / Twitter	Video – lay member (AB)	533	129 views	0	1	Anonymous	23/11/2021	We're consulting on making our policies the same across Bedfordshire, Luton and Milton Keynes. Have your say about future services by taking part! www.blmkccg.nhs.uk/PolicyConsultation	Video – clinical lead (SM)	216	69	3	1	1	Bpha	23/11/2021	Have your say about healthcare policies in BLMK www.blmkccg.nhs.uk/PolicyConsultation #BLMKWhatsYourView	Public Consultation Image	52		54	2		
23/11/2021	(6) NHS Bedfordshire, Luton and Milton Keynes CCG ♡ on Twitter: "Have a question about our consultation on aligning policies across BLMK? Come along to our online engagement session Tuesday 30 November, 6-7:30 pm, you must book in advance. Information on our consultation page https://t.co/3928YKf8IZ #BLMKWhatsYourView https://t.co/VPresdME3T" / Twitter	Image – Drop-in sessions	279		0	1	@BedfordPp	24/11/2021	Have a question about our consultation on aligning policies across BLMK? Come along to our online engagement session Tuesday 30 November, 6-7:30 pm, you must book in advance. Information on our consultation page www.blmkccg.nhs.uk/PolicyConsultation #BLMKWhatsYourView	Image – Drop-in sessions	185		2	0	0		24/11/2021	Have a question about our consultation on aligning policies across BLMK? Come along to our online engagement session Tuesday 30 November, 6-7:30 pm, you must book in advance. Information on our consultation page www.blmkccg.nhs.uk/PolicyConsultation #BLMKWhatsYourView	Engagement session image	40		45	2		
23/11/2021	We're consulting on making our policies the same across Bedfordshire, Luton and Milton Keynes. Have your say about future services by taking part!	Video – clinical lead (SM)	1493	263 views	0	2	@BedfordTweets Anonymous Quote Tweet	25/11/2021	Give us your views on how we commission services for people in Bedfordshire, Luton and Milton Keynes www.blmkccg.nhs.uk/PolicyConsultation	Image – Tell us your views	204		2	0	1	Anonymous	25/11/2021	Give us your views on how we commission services for people in Bedfordshire, Luton and Milton Keynes www.blmkccg.nhs.uk/PolicyConsultation	Public Consultation Image	47		48	1		
23/11/2021	NHS Bedfordshire, Luton and Milton Keynes CCG ♡ on Twitter: "Have your say about healthcare policies in BLMK https://t.co/3928YKf8IZ	Image – Drop-in sessions	318		0	1	@tweet_bpha	26/11/2021	Give us your views on how we commission services for people in Bedfordshire, Luton and Milton Keynes www.blmkccg.nhs.uk/PolicyConsultation	Video – clinical lead (SM)	222	59	5	4	1	Anonymous	26/11/2021	Give us your views on how we commission services for people in Bedfordshire, Luton and Milton Keynes www.blmkccg.nhs.uk/PolicyConsultation	Video – clinical lead (SM)	72	33	72	1		
25/11/2021	NHS Bedfordshire, Luton and Milton Keynes CCG ♡ on Twitter: "Give us your views on how we commission services for people in Bedfordshire, Luton and Milton Keynes https://t.co/3928YKf8IZ #BLMKWhatsYourView https://t.co/LqF1Dyr7k2" / Twitter	Image – Tell us your views	188		0	0		01/12/21	Give us your views on how we commission services for people in Bedfordshire, Luton and Milton Keynes www.blmkccg.nhs.uk/PolicyConsultation #BLMKWhatsYourView	Video – clinical lead (SM)	4.3K	1.9K	63	3	8	Central Bedfordshire Council Gravenhurst Parish Council Walton Community Council Access Bedford Biggleswade Council	30/11/2021	Give us your views on how we commission services for people in Bedfordshire, Luton and Milton Keynes www.blmkccg.nhs.uk/PolicyConsultation #BLMKWhatsYourView	Public Consultation Image	58		59	4		
26/11/2021	Give us your views on how we commission services for people in Bedfordshire, Luton and Milton Keynes http://blmkccg.nhs.uk/PolicyConsultation… #BLMKWhatsYourView	Video – clinical lead (SM)	204	47 views	0	0		1/12/2021	Have your say! Join in our BLMK Policy alignment consultation and share your view! #NHS #Gluten-free #Pharmacy #Fertility #BLMKWhatsYourView	Image – Tell us your views	392		10	1	0		01/12/2021	Give us your views on how we commission services for people in Bedfordshire, Luton and Milton Keynes www.blmkccg.nhs.uk/PolicyConsultation #BLMKWhatsYourView	Video – clinical lead (SM)	34	11	35	1		
30/11/2021	Give us your views on how we commission services for people in Bedfordshire, Luton and Milton Keynes www.blmkccg.nhs.uk/PolicyConsultation #BLMKWhatsYourView	Image – Tell us your views	312		0	0		04/12/2021	Have your say about healthcare policies in BLMK www.blmkccg.nhs.uk/PolicyConsultation #BLMKWhatsYourView	Image – Tell us your views	196		1	0	0		02/12/2021	Have your say about healthcare policies in BLMK www.blmkccg.nhs.uk/PolicyConsultation #BLMKWhatsYourView	Public Consultation Image	41		45	1		
01/12/2021	Give us your views on how we commission services for people in Bedfordshire, Luton and Milton Keynes http://blmkccg.nhs.uk/PolicyConsultation… #BLMKWhatsYourView	Video – clinical lead (SM)	2609	494 views	8	12	@davesimpson21 @BedsCHS @LutonCommNHS @MartinHumbersto @CllrKnight @BiggleswadeTC @ComActMK @letstalkcentral @WandGTC @Healthwatch_cb @CateThorne	07/12/2021	We're consulting on making our policies the same across Bedfordshire, Luton and Milton Keynes. Have your say about future services by taking part www.blmkccg.nhs.uk/PolicyConsultation #BLMKWhatsYourView	Image – Tell us your views	150		0	0	0		04/12/2021	Have your say! Join in our BLMK Policy alignment consultation and share your view! #NHS #Gluten-free #Pharmacy #Fertility #BLMKWhatsYourView	Public Consultation Image	51		53	1		

Social media log

Twitter								Facebook									Instagram							
Date	Post	Image / Video	Impressions	Video watched	Likes	Retweets	Retweet/Quote tweet by	Date	Post	Image / Video	Reach	Video watched	Engagement	Likes	Shares	Post shared by	Date	Post	Image / Video	Reach	Video Views	Impressions	Likes	
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04/12/2021	Have your say! Join in our BLMK Policy alignment consultation and share your view! #NHS #Gluten-free #Pharmacy #Fertility #BLMKWhatsYourView	Image – Tell us your views	272		0	0		11/12/2021	We're consulting on making our policies the same across Bedfordshire, Luton and Milton Keynes. Have your say about future services by taking part. www.blmkccg.nhs.uk/PolicyConsultation #BLMKWhatsYourView	Image – Tell us your views	271		1	1	0		09/12/2021	We're consulting on making our policies the same across Bedfordshire, Luton and Milton Keynes. Have your say about future services by taking part www.blmkccg.nhs.uk/PolicyConsultation #BLMKWhatsYourView	Public Consultation Image	37		37	2		
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20/12/2021	Tomorrow is the last day! Share your opinions and get involved with BLMK consultation on policy alignments. We want your views on gluten-free food, over the counter medicines and fertility services... Click on the link to take part! #BLMKWhatsYourView	Video – clinical lead (FG)	1068	231 views	1	1	@DaveTheMayor																	
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BLMK CCG, Policy Alignment Public Consultation

Social media log

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21/12/2021	It's the last day! Ends at midnight. Share your opinions and get involved with BLMK consultation on policy alignments. We want your views on gluten-free food, over the counter medicines and fertility services... Click on the link to take part! #BLMKWhatsYourView	Video – clinical lead (FG)	303	70 views	0	0																		
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9th December 2021

Healthwatch Milton Keynes Board response to the Consultation: Aligning Policies across Bedfordshire, Luton and Milton Keynes – BLMK CCG

For the attention of: Richard Alsop, Director of Commissioning and Nicky Poulain, Director of Primary Care

I am writing to thank you for the invitation to provide a formal organisational response the consultation on the Alignment of Policies across Bedfordshire, Luton and Milton Keynes.

Our response represents our position based on what we have heard from the patients and public of Milton Keynes but in our response have considered the context as a BLMK wide exercise.

Gluten Free

It is the position of Healthwatch Milton Keynes that BLMK CCG should offer prescribing of Gluten Free Bread and Flour mixes and align its policy position with that recommended by NHS England and the Department of Health and Social Care. This is the optimal position to ensure health equality for people across BLMK as an Integrated Care Service and the Country.

In April 2019 Healthwatch Milton Keynes published a report on Gluten Free Prescribing[1], where we highlighted the difficulty patients were having in accessing the Individual Funding Request (IFR) process and the challenges for those on low incomes to afford Gluten Free foods. We recommended to Milton Keynes CCG that socio economic factors should be allowed as a part of the IFR process. This recommendation was not supported by MK CCG. We understand that the Bedfordshire and Luton joint prescribing formulary and the Milton Keynes prescribing formulary are being aligned but in Milton Keynes, a decision has been taken to retain the Individual Funding Request (IFR) process for Gluten Free Food Prescriptions and importantly, the IFR does not take an individual's financial circumstances into consideration, when reviewing the request.

The public Case for Change document sets out: "*The former Bedfordshire and Luton CCG areas have a process for those on universal credit (i.e. those most at risk from the loss of gluten-free food prescribing) to enable them to continue to access gluten-free food via community pharmacists. Within Milton Keynes, the former CCG had an exceptional cases appeals process for those at risk of dietary neglect, which also allows patients at risk to continue to access these foods. It is not envisaged that this clinical decision will change for any area. Through an alignment of these processes those patients could still access these foods".* This does not make it clear that patients in Milton Keynes will have the same access

[1] Healthwatch Milton Keynes Gluten Free Prescribing report

to Gluten Free prescriptions, based on their financial circumstances as those patients in Bedfordshire and Luton following the alignment of policies. The decision taken to keep the prescribing formulary separate in Milton Keynes will mean that whilst the policies may align at the end of the consultation, access to treatment and health equality will not. This does not assure us that patients in Milton Keynes will have equitable access to treatment and that existing health inequalities across BLMK will continue and are at risk of future growth.

Fertility Treatment

Healthwatch Milton Keynes do agree in making this option available to a broader group of residents including those with protected characteristics but want to stress that the law is clear that these criteria should apply equally to opposite-sex and same-sex couples and whilst the consultation documentation sets out that the decision to proposed broadening the entry point to fertility treatment was recommended by the BLMK Equality Diversity and Inclusion Group, it would be unlawful for this policy not to be broadened out.

Whilst we appreciate budgetary limitations, we cannot support the "levelling down" of access to fertility treatment due to a legal requirement to include wider groups, and positioning this as a "levelling up" of health inequalities. Whilst it may achieve equality in access, all people included within the policy will not be able to receive the optimal number of treatments to successfully conceive a child and this may have longer term impacts on individuals not considered within this case for change.

It is the position of Healthwatch Milton Keynes that BLMK CCG should offer fertility treatment in line with the NICE recommendations[2]. This is the optimal position to ensure health equality for people across BLMK as an Integrated Care Service and the Country.

Milton Keynes Pharmacy First Minor Ailment Scheme

Healthwatch Milton Keynes notes the data set out in the Case for Change document which highlights the decreased use of the Pharmacy First Minor Ailment Scheme over time but are concerned about the assumptions being made within the Case for Change as the reason for the decline.

When making an informed position within a consultation it is vital for the public to understand why the scheme was launched initially and this information isn't readily available. We note that the Pharmacy First Scheme, launched in April 2018, and recent guidance from NHS England together with the National Community Pharmacy Consultation Scheme now places greater emphasis on the importance of self-care, but the Minor Ailments Scheme had the same aims, with the addition to recognise that people on low incomes may need more financial support to self-care.

The ailments may be minor but even minor ailments can cause significant distress and require people to take time off work. Additionally, the cost of over-the-counter items may be prohibitive to those in receipt of free prescriptions. By removing the service, whilst it may mean more equal access to advice and over-the-counter medicine for all patients in BLMK it

[2] https://pathways.nice.org.uk/pathways/fertility#path=view%3A/pathways/fertility/in-vitro-fertilisation-treatment-for-people-with-fertility-problems.xml&content=view-node%3Anodes-access-criteria

does mean that people on low incomes in Milton Keynes, Bedfordshire and Luton will continue to face barriers to receiving equitable treatment and care.

We hope that BLMK CCG fully consider the final decision on the policy alignment consultation within the context of the ambition of the Integrated Care System to address and reduce health inequalities and in that, recognise the wider determinants that negatively impact on health, such as poverty.

Yours Sincerely,

Maxine Taffetani
Chief Executive Officer
Healthwatch Milton Keynes

Healthwatch Luton Board response to the Consultation: Aligning Policies across Bedfordshire, Luton and Milton Keynes – BLMK CCG

FAO Richard Alsop, Director of Commissioning and Nicky Poulain, Director of Primary Care

The Healthwatch Luton Board would like to provide a formal response to the consultation on the **Alignment of Policies across BLMK**: particularly focused on the Gluten Free element, with mention to the IVF/Fertility policy. We feel these elements of your policy will affect Luton residents negatively more than the other policy alignment and having reviewed your case for change documentation would like to state we do not support the current consultation proposals.

We would like to add that we understand the need in which to address economies of scale across BLMK and support an approach which does not negatively affect Luton residents.

Gluten Free

For Luton residents, we feel the policy alignment proposal on Gluten Free prescribing will, we feel, be a 'levelling down' for Luton residents. Engagement and consultation has been done with the Luton CCG in 2016/2017 with Healthwatch Luton's involvement, alongside Coeliac UK, and we heard Luton residents, being from a more deprived area, as well as statistically having more coeliac patients than other BLMK areas, resulted in Luton's residents needing and using where required the prescriptions more.[1] Aligning this policy with other BLMK areas, such as Bedford and Milton Keynes, who have less coeliac patients, and higher income capacity does not feel fair to our residents.

The case for change document cites 'in order to provide equal access to services we need to move to a single policy for each service[2]' but as Healthwatch Luton Directors, we feel this alignment for coeliac residents in Luton will not provide an equal access – as the equity of numbers of coeliac patients linked with the higher deprivation is the placed-based reason for having prescriptions still available for Luton residents currently.

There is a longer-term effect of removing this option for Luton residents, to ensure a single policy for each service, which is the health detriments which will affect the Luton health system once these options are removed, such as increased risks of osteoporosis, deficiencies, polyps, cancer of the bowels, spleen conditions etc[3]. It would be helpful in your response for Healthwatch Luton Directors to be assure our residents these aspects have been reviewed in the case for change documentation, and how they will be managed if foreseen.

[1] Brief Summary Report – Healthwatch Luton engagement with LCCG 2017 (attached)
[2] Consultation - Aligning policies across Bedfordshire, Luton and Milton Keynes - BLMK CCG
[3] From 2016 Engagement with Luton residents – Quote from a Luton CCG staff member working with Healthwatch Luton

To that end, with the last open engagement being done with people affected by coeliac in 2017 in Luton– we feel this open consultation without targeted engagement and work focused with Coeliac UK nationally and locally, will not be a fair representation of those who will be affected by this policy.

We do not support this policy alignment.

Fertility Treatment

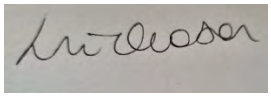
Healthwatch Luton do agree in making this option available to a broader group of residents including those with protected characteristics, but do not agree that altering the cycle options for Luton residents from x3 on the NHS to x 1 would be a positive aspect. Whilst we understand the need to provide 'equal options to residents' – we feel again this policy alignment proposal 'levels down' Luton residents options, rather than reviewing the population management of Luton residents and the percentage of protected characteristics in our residents, requiring larger numbers of cycles.

We do not support this policy alignment.

Furthermore, Healthwatch Luton have asked in a series of meetings for transparency to Luton residents on how commissioning decisions are being made both at scale (across Bedfordshire Luton and Milton Keynes) and what can be commissioned locally at Place Based level in Luton – to suit Luton residents.

Without this transparency the Healthwatch Luton Board Directors have a concern that the CCG's alignments and changes in policy and reviews is financially motivated and does not take into account the extremely specific fundamentals of Luton's Population health and wider determinants. The 'clear differences in these policies[4]' we feel reflect the clear differences in our population in Luton – so we would want to understand more than financial motivation to align Luton's policy with BLMK – for the benefit of the Luton resident.

We are happy to discuss this in more detail but wanted to share our views on your current consultation.



Lucy Nicholson

Chief Executive, Healthwatch Luton

On Behalf of Healthwatch Luton Board of Directors

[4] Consultation - Aligning policies across Bedfordshire, Luton and Milton Keynes - BLMK CCG

Brief Overview of Feedback

Event	Over the Counter and Gluten Free food consultation
Date of event	01.12.17

My concerns about the proposals are:
There needs more encouragement for people to talk to the pharmacist about minor conditions before seeing their GP. It requires educating people that the pharmacist has the knowledge to help or advise when a GP appointment is relevant.
I think OTC medication should not be handed out on prescription – Gluten Free flour and pasta should be available to poorer families.
Some people will keep taking indigestion medication and not going to the doctors – this could lead to serious stomach problems.
Children with fever can have sepsis or meningitis etc so some parents can be put off going to the doctor if you say they do not need to go.
Paracetamol or meds in supermarkets are limited to two per person and also the age restrictions.
The continuous use and not consulting a doctor can lead to serious complications, especially in children.
Poorer families in Luton need prescriptions – its not a choice
There are more gluten free residents in Luton – so needs to be looked at differently, along with poverty

The proposals are a good idea because:
If launched properly it should encourage people to accept responsibility for their own health. A large number of the public go to the GP because they want a 'quick fix' for usually fairly minor complaints.
Money can be saved for more important medication that can save lives.
I agree the waste, but the new system cutting down on the amounts issues should help solve this problem.

I would like to see money spent on:
A better understanding of the implications and effects of not following a gluten free diet on people diagnosed with Coeliac. It is not as insignificant as the LCCG seem to believe.

Other areas money could be saved:
Better control over quantities of medicines prescribed, also look at getting the government to support the NHS as needed.
Perhaps offering prescriptions free to those who have a certain condition, is just relevant to their condition, and not everything might discourage them from going to the GP about everything when they could self medicate/self health.

Other comments:
It concerns me that the CCG consider Gluten Free prescriptions as not particularly of a good value for money.
All those who completed an evaluation form, said they felt the forum was informative and they were able to express their thoughts and opinions freely. They agreed (or agreed a lot) that staff were friendly and approachable and they would attend another event held.

Community Interest Company No 8385413
21-23 Gadsby Street
Bedford MK 40 3HP

To:
Richard Alsop
Director of Commissioning, Contracting and Transformation

Nicky Poulain
Director of Primary Care

Bedfordshire, Luton and Milton Keynes Clinical Commissioning Group
Capability House
Wrest Park
Silsoe
MK45 4SH

20 December 2021

Dear Richard and Nicky

Re: Public Consultation. Aligning policies across Bedfordshire, Luton and Milton Keynes.

Thank you for inviting us to submit the views of Healthwatch Bedford Borough on the proposals detailed in the Case for Change document, currently out for public consultation, in relation to fertility services, gluten-free food prescribing and the pharmacy first minor ailments scheme.

We acknowledge the rationale behind these proposals, to address unwarranted variation in access by providing equal access to the services commissioned across Bedfordshire, Luton and Milton Keynes (BLMK), moving to a single policy for each service. We also recognise the financial constraints on the BLMK CCG health budget.

We do, however, believe that any move to equalise access to services should follow the principle of levelling up. For this reason, we are disappointed that the preferred options will result in the withdrawal of some services from patients outside of Bedford Borough. As the consumer champion for health and social care provision for residents of Bedford Borough, the primary responsibility of Healthwatch Bedford Borough is to safeguard the needs of the local population. We note that these proposals are not disadvantageous to the people of Bedford. We also welcome the extension of fertility services to some people who were previously excluded, thus addressing inequalities within current provision across the whole of BLMK. On these grounds, Healthwatch Bedford Borough do not object to the preferred options, as specified in the consultation document.

Throughout this consultation period we have encouraged individuals to make their views known. By responding to this consultation, residents of Bedford Borough have been given the opportunity to influence decision-making and shape the provision of services that

best respond to local need.

Yours sincerely

John Wright
Chair, Healthwatch Bedford Borough

"A strong voice for local people"

MINUTE REFERENCE FROM BEDFORD BOROUGH COUNCIL'S HEALTH OVERVIEW AND SCRUTINY COMMITTEE HELD ON 6 DECEMBER 2021

28. BLMK CCG POLICY ALIGNMENT (FERTILITY SERVICES, GLUTEN FREE FOODS AND MILTON KEYNES PHARMACY FIRST)

Further to Minute 7 (13 September 2021), Members discussed their response to the consultation in relation to BLMK CCG's policy alignment concerning fertility services; gluten free foods; and Pharmacy First. The Committee focussed their responses on questions 5, 6, 8, 9, 11 whereby the following comments were noted:

- In terms of the case for change and reference to the NICE guidelines, it was felt that it had been worded disingenuously. It stated that NICE guidelines were provided for fertility services, however in the case for change it did not make reference to those guidelines. The guidelines were for women under 40 years of age whereby the recommendation was to offer three full cycles, however the preferred option in the document was for one cycle. Therefore, BLMK CCG should have outlined what the NICE guidelines were in order to be completely open and transparent. It was also felt that the NICE guidelines had been down-played in terms of how the case for change had been presented, stating that they were recommendations only, however NICE guidelines were used by local commissioners and providers whom had a responsibility to enable the guidelines to be applied, particularly when individual service users wished to use them. It was within the complex of local, national and budgetary priorities, however NICE guidelines should not be down-played as they were important and evidence based;
- Members had been previously reassured by BLMK CCG that people on low incomes would continue to receive gluten free food prescriptions from their GP if they were unable to access gluten free foods from supermarkets within Bedford Borough. However, this service was being removed from Milton Keynes;
- It looked like services were being dissolved rather than them being raised up. From the report, it looked to be financially and priority related which was understandable with current NHS pressures, however it was felt that Health Services should be improving and not being reduced. As the CCG area increased, there was a need to ensure that services were not being reduced because of finances, particularly when funding has being made available to the NHS, however did not appear to be filtering through to the CCGs, and if so, why were they not using it rather than reducing services and policy aligning Bedford with Milton Keynes and Luton;
- Pharmacy First Services could help families on a low income, especially for minor illnesses and prescriptions which would then help to ease pressures on the NHS and GP services. If the service could be provided in Bedford it would be very helpful for families and individuals who were struggling financially as it was considered to be a quick and more convenient service;

- It felt like some health services were being provided by the lowest common denominator, as an unintended consequence of bigger CCGs covering a larger region, playing areas off against each other by selecting the one with the lowest level of service which was then taken forward across the CCG which was not right;
- This was an opportunity to increase health services in Bedford Borough to match those in Milton Keynes and Luton, however it was felt that it had done the reverse and decreased services. There would not be any detrimental effects on Bedford Borough residents as they did not have access to such services in the first place, however it was an opportunity for the CCG to upscale services that the Borough already had to match Milton Keynes and Luton. Once the consultation had finished, the Committee would invite the CCG to a future meeting to explain their implementation process;
- In terms of IVF treatment, there was an enhancement for Bedford Borough residents, as services would be expanded beyond normal heterosexual relationships;
- It felt like services were being levelled down rather than increasing services across the CCG area. Questions had been raised regarding fertility treatment options and taking into account NICE guidelines in relation to three cycles of fertility treatment;
- Health services should all be levelled up, however this would probably mean cuts elsewhere, which was particularly worrying; and
- Financial and demand pressures on the NHS were understood, however, this was an opportunity to increase services for residents within the Borough. Therefore, BLMK CCG was requested to consider this Committee's response, as it felt like the opportunity had been missed.

The Vice-Chair requested that the Senior Officer and Policy Adviser (Health) drafts a response to the consultation on behalf of the Committee and circulate it to Members for comment, prior to it being submitted to BLMK CCG for consideration.

RESOLVED:

i) That the Committee agreed its response to the consultation as recorded in the minute above.

ii) That, on behalf of the Committee, the Senior Officer and Policy Adviser (Health) drafts a response to the BLMK CCG consultation regarding their policy alignment and circulates it to the Members of this Committee for comment.

iii) That the Committee's final response be submitted to the BLMK CCG prior to the consultation deadline on 21 December 2021.

The Association of UK Dietitians

Policy Statement

Gluten Free Food on Prescription

Summary

Coeliac disease is a lifelong autoimmune condition caused by an abnormal immune response to eating gluten. It is one of the most common gastrointestinal conditions that require dietetic support. If untreated, coeliac disease leads to extensive intestinal villous atrophy that causes malabsorption of essential nutrients such as calcium, iron, vitamin B_{12} and folate. In the long term, gluten consumption in coeliac disease can lead to complications such as osteoporosis, lymphoma and small bowel cancer, depression and infertility. A gluten-free (GF) diet is the sole treatment for coeliac disease and many patients find this extremely challenging. The provision of GF staple foods on prescription plays an essential role in supporting people with this condition to facilitate adherence to their treatment; a strict, life-long GF diet. Excluding gluten from the diet requires removal of many staple food items such as breads and pasta, additionally gluten is found in many processed foods, requires people to develop skills and knowledge to navigate the numerous sources of gluten in and out of the home environment.

The BDA states that:

- Coeliac disease is a condition that warrants the continued availability of staple GF foods on prescription (such as breads, flour mixes and pasta). It is a lifelong autoimmune disease with serious complications associated with non-adherence to a GF diet. The ingestion of even small amounts of gluten causes damage to the lining of the small intestine leading to inflammation and malabsorption, and therefore subsequent nutritional deficiencies, in addition to an increased risk of osteoporosis, depression, infertility and malignancy.

- People diagnosed with coeliac disease require access to staple GF foods on prescription. National prescribing guidelines (1) recommend a monthly unit allowance that, ensures equality in treatment for all with the diagnosis of coeliac disease. Gluten free prescriptions:

    - help ensure equitable access to staple GF foods.
    - maximise adherence and facilitate the prevention of long-term medical consequences associated with gluten consumption.
    - support individuals in meeting raised nutritional requirements, as many GF foods on prescription are fortified with calcium and B vitamins.
    - reduce the financial burden of purchasing staple GF foods.
    - Dietitians may make recommendations that deviate from the national prescribing guidance; these will be based on expert assessment, taking into

account the individual's clinical condition, overall nutritional requirements, and external influencers of, the only treatment, GF dietary adherence.

- In line with the NICE Quality Standard for Coeliac Disease (2), all patients diagnosed with Coeliac Disease should receive an annual review, preferably with a dietitian with expertise in coeliac disease. This will support GF dietary adherence and nutritional adequacy, allow symptoms to be reviewed and further appropriate information, advice and support to be provided.

- The NHS should take advantage of new and innovative models for the provision of GF foods using dietetic-led (e.g., dietitian prescribing in Rotherham) or pharmacy-led schemes (e.g., Gluten Free Food Service in Scotland), in Wales Hywel Dda University Health Board has successfully trialed a card payments scheme. These models have been found to be cost effective and convenient for patients and healthcare professionals.

- The cost to the NHS of supplying prescribed GF foods is complex involving manufacturers, pharmacies and wholesalers. In some cases, additional handling charges are placed by wholesalers. The BDA urges Clinical Commissioning Groups (CCGs) in England and other NHS providers to work with pharmacists and local healthcare professionals in getting the best price for providing GF food on prescription. It is possible to reduce the overall costs of supplying GF staple foods via new innovative schemes that save GP time and provide better cost control.

- Where provider organisations are reviewing the provision of GF staple foods on prescription, the BDA strongly advises that Coeliac UK, local dietitians, gastroenterologists, pharmacy prescribing leads, GPs and patient representatives are fully involved in the review process and monitoring any impact of changes. In England, the BDA would recommend that providers should, as a minimum, adhere to the outcomes of the national consultation that recommended GF bread and GF multipurpose mixes remain on prescription. Dietetic and patient representation is particularly important when considering rationalisation of the categories and brands of GF foods available so as to ensure the needs of the coeliac population in general, and the specific nutritional needs of each individual patient are understood and considered.

Background

A gluten free (GF) diet avoids all food products that contain gluten, this requires excluding all foods made from wheat, rye and barley and oats (not certified as GF). These grains are present in many of the staple foods in the UK diet (e.g., breads, flour, cereals, pasta) that provide a large proportion of the energy, fibre and several of the micronutrients needed to sustain life (3). Wheat, rye or barley may also be present in foods not considered at first appearance to contain gluten (for example sausages).

Patients on a GF diet are encouraged to consume naturally GF foods (including rice and potatoes). However often it is not realistic, nutritionally appropriate, convenient nor enjoyable to base the diet simply on rice and potatoes (for example school packed lunches). This means that GF alternatives to many 'staple foods' are regularly consumed.

Dietitians have a key role to play in the initial dietary assessment post diagnosis as well as monitoring annually (4) (5) (6). At an annual review, dietitians assess and advise on GF dietary adherence, including the best ways to use foods naturally GF as well as use

prescribed GF foods effectively in order to optimise dietary adherence and overall nutritional status.

Current provision

- The national prescribing guidelines (1) focus on recommending the prescription of reasonable amounts of staple GF foods as a number of units on a monthly basis based on age, sex and average energy requirements.

- The UK government consultation for provision of GF food in England (7) resulted in the recommendation and subsequent legislation that, in England, only GF Breads and GF multipurpose mixes are available on prescription for all people with coeliac disease. In England, individual CCGs decide on what level of provision is available, there remains considerable variation in provision across CCGs. Prescriptions have a fixed cost unless patients are exempted.

- In Scotland, GF prescribing is managed through a centrally funded, community pharmacy-led supply service called the Gluten Free Food Service. All prescriptions are free (8).

- In Wales, a full range of GF products continue to be available on prescription. Hywel Dda University Health Board has successfully trialled a card payments scheme, which is being rolled out on a voluntary basis throughout the board area. Welsh government are considering the outcomes of the trial. All prescriptions in Wales are free (8).

- In Northern Ireland, the Health and Social Care Board supports the prescription of GF staples both in terms of the quantities and range as within the national prescribing guidelines. All prescriptions are free (8).

Rationale for provision of GF foods on prescription

Receiving GF food staples on prescription will:

a) Maximise adherence:

Many patients find it challenging to manage a life-long GF diet. Adherence to a GF diet has been shown to be poor with 42 – 91% of people with coeliac disease adhering to a GF diet (9). The difficulties in adhering to a strict GF diet and the psychological impact such as anxiety and depression have been highlighted in a number of research papers (10) (11) A number of factors can affect adherence, including access to GF food on prescription (12) (13).

Current identified risks of non-adherence to a GF diet include: infertility, anaemia (iron deficiency anaemia and megaloblastic anaemia) and other nutritional deficiencies (calcium, fibre, folate deficiencies), osteoporosis, osteopenia, increased risk of fractures, and malignancy. In children long term complications include shorter stature and delayed puberty (14) (15) (16) (17).

b) Meet nutritional needs (in particular fibre, iron and calcium) and prevent long term consequences of non-adherence to the GF diet at every life stage.

Prescribed GF foods contribute substantially to the nutrient intake of people with coeliac disease (18). Commercially available GF foods are less likely to be fortified than their prescription only counterparts, only 16% of commercially available GF white breads were fortified with calcium, compared to 53% of prescription GF white breads (19). Calcium is an essential micronutrient, known to be low in the diets of those with coeliac disease. Other micronutrients and minerals such as zinc, magnesium and Vitamins D and B12 have also been found to be lacking in gluten-free diets (20).

c) Reduce the financial burden of purchasing GF foods

GF foods are up to five times more expensive than gluten containing options (21) (22). The high cost of GF foods can impact upon GF dietary adherence (23). GF foods on prescription provide a key support for people on low income, those on welfare benefits and the elderly on pensions.

The NICE Quality Standard recognises that "Gluten-free products are more expensive and are usually only available from larger retailers, making access more difficult for people on low incomes or with limited mobility." (2)

d) Ensure equitable access to GF products.

Budget supermarkets and convenience stores, even the small 'local' supermarket outlets, typically have no GF foods (21) (22). This problem is exacerbated in more rural and isolated areas where a patient's choice of shops close to home is limited additionally in these areas supermarket online delivery is often limited too, with required minimum spends. This will have a particular impact on those on a low income, or those more vulnerable patients, who are more likely to shop in small shops close to home and budget supermarkets.

Staple foods such as bread and pasta are particularly important for children – as they provide sufficient energy for growth and development. For school age children these staples are very important and are used to make up packed lunches when there is limited availability of GF school meals.

Alternative models of provision

The budgetary pressures on the NHS are significant. It is important that providers consider the instigation of innovative approaches to GF prescription so as to improve accessibility and limit cost increases. In the last few years, a number of approaches have been trialed and adopted. Outcomes have been very positive in terms of acceptability to the patient and healthcare professionals. These innovative models (led by or involving dietitians) can be effective in controlling and reducing the cost of GF prescriptions while ensuring equitable and straightforward access to prescription items for patients. The following innovative services are in operation in the UK:

- Pharmacy-led scheme utilised in Scotland (24) and some parts of England (25), or a voucher/debit card model with dietetic follow-up can improve adherence (by reducing the financial impact on patients) and maintain provision while reducing the impact on GP time and reducing wastage.

- A successful dietetic led service is operating in Rotherham, where Dietitians have full control of the prescribing budget for gluten free and other Nutritional Borderline Substances (NBS), may offer a sound alternative solution to ensuring that products are prescribed efficiently and patients receive the best standard of care and support cost effectively (26).

When considering the costs of prescribing GF foods, it is important to be mindful of the cost of the long-term health consequences of poor GF dietary adherence. Complications, such as those listed below, will impact the frequency of visits to GPs and even secondary and tertiary health care facilities - with associated financial implications for the NHS.

When calculating the consequences of non-adherence to a GF diet the increased risk of and the cost of treating the following must be considered:

- Depression
- Infertility
- Anaemia – iron deficiency and megaloblastic anaemias
- Osteoporosis
- Osteopenia
- Fracture
- Cancer – lymphoma and small bowel cancer

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This document has been prepared and reviewed by the Coeliac Clinical Leads of the BDA Gastroenterology Specialist group.

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20 December 2021

Dear Ms Garnett,

Re: Consultation on the future of gluten free food supply in Bedfordshire, Luton and Milton Keynes.

Following the launch of your consultation on gluten free prescribing, we are submitting our formal response for consideration.

Coeliac UK is the charity for people diagnosed with coeliac disease and dermatitis herpetiformis who have been medically prescribed a gluten free diet, to maintain good health and wellbeing. For more than fifty years, we have been providing independent, trustworthy advice and support to people with the condition.

We believe there is a compelling case for provision of gluten free bread and flour mix on prescription for those with a diagnosis of coeliac disease or dermatitis herpetiformis (DH) in the Bedfordshire, Luton and Milton Keynes (BLMK) area (Option 2 as laid out in your consultation document).

The reasons are summarised in the following key points and expanded within the attached:

- the significance of a medically prescribed gluten free diet for people with coeliac disease or DH
- the barriers to maintaining a gluten free diet without support
- the impacts of withdrawal of provision and
- the negative implications of withdrawal (Option 1) on deprivation and health inequality, especially within the BLMK area.

In conclusion, we strongly recommend the adoption of Option 2 in recognition of the ongoing significant cost, access and availability challenges regarding the gluten free diet. Prescribing uptake figures in Luton suggest a notable degree of self-selection is already taking place, without the need for further restrictions. We have real concerns as to the impact of withdrawal of provision on the most vulnerable communities.

We are not persuaded that existing processes in place in Bedfordshire or Milton Keynes adequately support vulnerable members of the coeliac community to access gluten free prescribing support and would therefore caution against adoption of Option 1, as proposed.

I look forward to hearing from you and would welcome the opportunity to further discuss the points raised.

Yours sincerely,

Tristan Humphreys

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Coeliac UK – consultation response: gluten free food prescribing in BLMK

About Coeliac UK

Coeliac UK is the charity for people diagnosed with coeliac disease and dermatitis herpetiformis; a patient group who have been medically prescribed a gluten free diet, to maintain good health and wellbeing. For more than fifty years, we have been providing independent, trustworthy advice and support to people with the condition. We currently have over 65,000 active members and have had more than 200,000 over the charity's lifetime, which is similar to the estimated diagnosed prevalence of coeliac disease within the UK. We provide food information services to assist people with managing their gluten free diet, a Helpline with access to Registered Dietitians and advocate for the coeliac community.

1. The significance of the gluten free diet

1.1. Coeliac disease is an autoimmune disease caused by a reaction to gluten, found in wheat, barley and rye. Adherence to the gluten free diet remains the complete medical treatment and having coeliac disease therefore requires significant dietary modification. Rates for adherence to the gluten free diet can vary between 42-91% [1] and access to gluten free staples on prescription can be related to adherence [2].

1.2. Following a strict gluten free diet allows the gut to heal and reduces the risk of long term complications. Non adherence to the gluten free diet is associated with an increased risk of long term complications, including osteoporosis, ulcerative jejunitis, intestinal malignancy, functional hyposplenism, vitamin D deficiency and iron deficiency [3]. For children, non-adherence to the diet can have additional consequences including faltering growth and delayed puberty [4]. These long term complications will impact upon quality of life for the patient and treating these complications will result in financial implications for the NHS.

2. Barriers to maintaining a gluten free diet without prescribing support.

2.1. Availability: Although the variety and range of gluten free foods has increased in retail, issues remain around the availability of gluten bread in particular with 66% of participants in a recent study indicating they had to visit multiple stores in order to obtain the GF produce they needed [5]. Furthermore gluten free staple foods are not readily available to purchase in budget supermarkets and convenience stores [6,7]. Hanci and Jeanes publication on the accessibility of gluten free staples concludes that "The gluten free food desert within convenience and budget stores will continue to disproportionately impact poor socioeconomic cohorts, the elderly and physically disabled"[8]. Access to staple gluten free food on prescription is especially vital for the most vulnerable such as the elderly or those with limited transport options and policy makers must consider the needs of all patients, not just the people who have the economic and physical means to shop in large supermarkets or have a network of support around them.

2.2. Cost: Gluten free staple foods are significantly more expensive than gluten containing equivalents. Research shows that on average they are 3-4 times more expensive [6,7]. In the case of bread, someone purchasing the cheapest gluten containing loaf of bread would have to pay nearer 8 times as much for a gluten free loaf. Gluten free staple foods on prescription therefore help to address the financial

burden for people on fixed or low incomes. Further, no narrowing in cost difference over time has been observed [8]. Indeed, research from Vriesekoop et al. found that between 2015 and 2019, the relative price differential between gluten containing and gluten free produce actually increased across all UK supermarkets [5].

2.3. The role of gluten free substitute foods in the diet: Starchy carbohydrates are an important component of a healthy diet and the Public Health England Eatwell Guide recommends that carbohydrates should contribute 50% of energy to the diet. Complete replacement of gluten containing staple foods is not easy and gluten free substitute foods are important for both practical reasons and for their nutritional contribution to the diet.

2.4. Daily calcium recommendations for people with coeliac disease are higher (1000 mg/day) than the general population (700 mg/day) [9] therefore including good sources of calcium in the diet is particularly important for people with coeliac disease.

2.5. Cereals and cereal products contribute significant amounts of iron and calcium to the diet. Data from the National Diet and Nutrition Survey shows that cereals and cereal products contribute 44% of total iron intake and 30% total calcium intake to the diet [10]. The complete removal of cereals therefore has a significant impact on nutritional intake.

2.6. For example, replacing 72g (the equivalent of two slices) [11] of gluten free bread with a portion of rice containing the same amount of calories would reduce the iron content by 96% and the calcium content by 90%. Similarly, replacing gluten free bread with a portion of peeled, boiled potatoes containing the same amount of calories would reduce the iron content by 71% and the calcium content by 93%.

2.7. Those who would be most affected by the withdrawal of prescriptions are likely to be the least able to also manage the complexity of the multiple adaptions required to maintain the nutritional balance while also ensuring their diet remains gluten free [8].

3. The impact of withdrawal.

3.1. The cost of non-adherence: The average cost to the NHS of an osteoporotic hip fracture is £27,000 [12] – the equivalent to more than a lifetime's supply of gluten free prescribing for the majority of people. This is significant given that osteopenia and osteoporosis is found in 40% of adult patients at diagnosis of coeliac disease [13].

3.2. Health inequalities and impact on the vulnerable: As mentioned above withdrawal of prescribing is likely to most adversely affect vulnerable communities, those least able to absorb the additional financial cost of accessing gluten free staples or overcome the sparsity of access in more deprived or rural communities. Further, the complexity of the adaptations required to maintain a balanced diet make it ever more challenging for vulnerable groups.

3.3. Based on the ONS statistics for 2019/20 household expenditure the lowest income groups spent on average £34 a week on food and non-alcoholic drink which represented 14% of their total weekly spend (£221) [14]. This is in comparison to households with the highest income who spent on average £98.70 per week on food and non-alcoholic drink which represented 8% of their total weekly expenditure (£1199.50) [14]. Approximately 70% of people who have lost access to gluten free foods on prescription, report that their weekly shopping bill has increased by an average £10, this is across all income brackets [15].

3.4. The impact of the increased expenditure on gluten free foods, due to a loss of access on prescription, means therefore the lowest income households' weekly expenditure on food and non-alcoholic drink has increased by 29%, from £34 to £44 and for the highest income households 10%, from £98.70 to £108.70. Based on the ONS statistics [14], households with the lowest income are now spending 20% of their total weekly expenditure on food and non alcoholic drink, up from 14%. The highest income households on the other hand are spending 9% of their total weekly expenditure on food and non alcoholic drink, up from 8%. This clearly demonstrates how withdrawing access to gluten free foods on prescription accelerates inequality and affects vulnerable patients the most.

3.5. The current Covid-19 pandemic further exacerbates these challenges. More than a fifth of people report having reduced income as a result of the pandemic and expenditure on food tends to be one of the first things to be cut back when finances are tight. Moreover food insecurity is higher amongst households with children [16] making it particularly important that such vital support for those living with a long term condition is maintained.

3.6. Research published by Muhammad et al. [17] explored the factors associated with adherence to the gluten free diet and differences between Caucasians and South Asians. A number of factors were identified as having a role in adherence to the gluten free diet, including understanding food labels, membership of Coeliac UK and access to gluten free food on prescription.

3.7. Not understanding food labels was significantly associated with poorer adherence to the diet. Of those who said that they did not understand food labels, 73% were not adherent to the diet. Not understanding food labels was found to be more common in South Asians (53%) compared to Caucasians (4%).

3.8. This research also supports continued access to gluten free food on prescription as respondents who were not receiving gluten free food on prescription had lower dietary adherence scores compared to those who did.

3.9. NICE quality standard for coeliac disease: The potential inequalities discussed above have also been highlighted in the National Institute of Health and Care Excellence (NICE) quality standard for coeliac disease. The standard highlights that the access issues, will in particular, affect people on low incomes and with limited mobility and highlights the following under equality and diversity considerations:

- Gluten free products are more expensive than gluten containing alternatives
- Gluten free products are usually only available from larger retail outlets
- Coeliac disease can affect multiple people within a household and this incurs additional financial burden

3.10. Review by the Department of Health and Social Care (DHSC): The review carried out by the DHSC on the future of gluten free prescribing was a substantial exercise that received an unprecedented number (almost 8,000) of responses from clinicians, professional bodies and patients. The decision to retain access to gluten free bread and flour mixes on prescription was based on a significant amount of evidence highlighting the issues of cost and availability to patients and the impact on patient health and long term cost to the NHS due to inability to comply with the gluten free diet. The DHSC report therefore warrants attention from commissioners.

3.11. Access to gluten free food on prescription is a service providing essential NHS support to help people manage a lifelong autoimmune disease. We are particularly

concerned that any further cessation of gluten free prescribing would result in increased health inequality due to the higher cost and lack of access to sustained availability of staple gluten free food in retail and would have a disproportionate impact on the most vulnerable.

4. Impact of the proposals on the most vulnerable communities in BLMK

4.1. Deprivation: As explored above, there are notable concerns regarding the impact withdrawal of gluten free prescribing could have on the most vulnerable, in particular the implications for those from the most deprived socio economic cohorts. With this in mind, it is of note that each of the former CCGs (Bedfordshire, Luton and Milton Keynes) cover areas of high deprivation and concerning health inequalities.

4.2. Bedfordshire is covered by two local authorities; Bedford Borough Council (supporting a population of 184,097) and Central Bedfordshire Council (supporting a population of 258,461) [18]. In Bedford borough, 11.4% of the population are in the 20% most deprived in England and this is the same for just under 8% in neighbouring Central Bedfordshire. A respective n=17 and n=8 of England's most deprived LSOAs can be found in these authorities [19], one in five children are living in poverty [20].

4.3. The borough of Milton Keynes, covered by Milton Keynes Council, has a population of 300,000 [18] with 11.1% of the population categorised as income-deprived and n=17 of its LSOAs are in the upper quintile for income deprivation [19].

4.4 The most urban and culturally diverse of the three areas, the former Luton CCG boundary covers a population of 237,690 [18]. In Luton local authority, 15.5% of the population is income deprived. Furthermore, n=34 of its 120 LSOAs are within the 20% most deprived in England. This places the authority in the top quantile for deprivation in England and places it in the 'Most income deprived' category according to the ONS [19].

4.5. Concerning uptake of support in Bedfordshire and Milton Keynes

4.6 Bedfordshire: Based on the CCG's stated population (442,558) [18] and the latest epidemiology results for diagnosed prevalence of coeliac disease [21] it is estimated approx. n=1,593 people may have a diagnosis of coeliac disease. Bedfordshire currently operates a process by which anyone on pension credit and universal credit can be recommended for ongoing support via a prior approval form filled out by their GP. For those not in receipt of income support, an individual funding request is required. Under this existing policy, only n=6 individuals are currently accessing prescriptions (0 in Bedford Local authority) across the area. This represents just 0.38% of the estimated diagnosed coeliac population in the CCG [22]. Taking into consideration that diagnosis of coeliac disease is lower in people who are most deprived [23, 24], this remains in stark contrast to the 10% of the CCG population that qualifies as income deprived [19]. We understand this model is preferred for adoption across BLMK under Option 1.

4.7 Milton Keynes CCG has a population of 300,000 [19] with n= 1,080 estimated to be diagnosed with coeliac disease based on the latest epidemiology data [21]. Again, the CCG has an exemptions policy where a form must be submitted by a healthcare professional, on behalf of the patient, requesting access to gluten free prescribing via an Individual Funding Request. Only four individuals are currently accessing gluten free prescribing via these existing measures, representing just 0.37% of the estimated diagnosed coeliac population [22]. This is again in stark contrast to the 11.1% of the population characterised as income deprived [19].

4.8 Whilst we recognise Option 1 provides one avenue for those 'at risk of dietary neglect to still be able to access' gluten free prescriptions when appropriate [25], the notably low uptake of this in Bedfordshire (0.38%) and Milton Keynes (0.37%) is of real concern [23] and casts doubt as to the effectiveness of existing processes for supporting the most vulnerable coeliac patients.

4.9 Impact of changes to coeliac population in Luton:

4.10 Luton CCG has a population of 237,690 [18] with an estimated n=856 to have a medical diagnosis of coeliac disease based on the latest epidemiology data [21]. Based on the CCG's figures (100 - 136 patients currently accessing support), this equates to only around 12 - 16% of those currently diagnosed and eligible to access to support on prescription [22]. While we don't have access to data for each individual currently accessing support, this figure tracks closer to the 15.5% of those categorised as income deprived across the area [19]. This suggests a significant degree of self-selection is already taking place within the Luton area, further that those capable of maintaining their diet without support have already opted not to access provision on prescription. This raises serious concerns regarding the impact of complete withdrawal (option 1) could have upon the coeliac population in Luton and how much slack is actually in the system.

4.11 Concerns regarding the adoption of Option 1 in BLMK

4.12 We understand the Bedfordshire exemptions model is the CCG's preferred approach to support access to vulnerable coeliac patients should Option 1 be approved. This is of real concern given the very low number (~0.4%) accessing support in this way in Bedfordshire [22]. Even allowing for a lower proportion of deprivation amongst the diagnosed coeliac population, this is clearly not in keeping with the expected uptake by those most vulnerable coeliac patients across the CCG.

4.13 The consultation report states that the CCG's preferred option is *'Option 1: To withdraw the gluten free bread and flour available on prescription in Luton, whilst ensuring patients at risk of dietary neglect are still able to access when appropriate, in line with Bedfordshire and Milton Keynes'* [25]. Yet in both cases, administrative and practical hurdles must be overcome in order to access this support. An individual must first be aware of their entitlement [26], be able to access a healthcare professional and able to effectively advocate for them self. This is particularly concerning given that the most deprived are less likely to be able to access a healthcare professional than less deprived peers [27].

4.14 In turn the individual must already be accessing other financial assistance such as Universal Credit or pension credit, each requiring significant administrative hurdles to be overcome. For example, the means tested pension credit has an uptake rate of 60% compared to 97% for the basic state pension [28].

4.15 For those not accessing income support, we understand an Individual Funding Request is required. We have reservations about this approach for a number of reasons. IFRs are administratively burdensome and also require GP or Dietitian time for completing the IFR form. While some vulnerable groups may require access to gluten free food on prescription in the long term (e.g. patients with learning difficulties), others may require short term support, e.g. due to changes in employment status. This may mean that the CCG would need to re-evaluate IFRs on a regular basis, adding to the administrative cost.

4.16 We would like to understand how you plan to monitor the impact on health and wellbeing of people with coeliac disease as a result of potential changes to gluten free food on prescription for patients with coeliac disease, if a policy change is approved. In particular we are concerned there is insufficient monitoring and evidence of the impact of prior withdrawal in Bedfordshire and Milton Keynes to justify adoption of these policies across BLMK going forward.

4.17 In addition, the National Institute for Health and Care Excellence (NICE) recommends that all patients with coeliac disease are offered an annual review in their updated clinical guideline, Recognition, Assessment and Management of coeliac disease (NG20, 2015). How many patients with coeliac disease have been offered an annual review and are currently accessing this support across the CCG? How will you ensure patients are able to access adequate dietetic support in the face of withdrawal of prescribing?

4.18 Finally, we understand gluten free prescriptions are the only such service in Bedfordshire and Milton Keynes whereby this exceptionality mechanism has been adopted. We are concerned that coeliac disease is subject to administrative requirements that comparable conditions are not and this itself causes inequality.

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Appendix 13

Response received in body of email from representative from Fertility Network UK

We are concerned by the proposals to change the provision of fertility services in Bedfordshire, Luton and Milton Keynes which will take the local area further away from what is recommended by the National Institute for Health and Care Excellence (NICE) as being both clinically and cost effective.

The “Case for Change” document suggests that NICE guidance has to be “considered within a local context when commissioning services”, but the document does not give reasoning as to what would affect the clinical or cost-effectiveness of fertility treatment within the Bedfordshire, Luton and Milton Keynes area. The fact that the CCG has accumulated historic debt is not a reason not to offer a clinically and cost effective treatment as recommended by NICE. We note that the three pre-existing CCGs delivered a cumulative in-year surplus of £14.1m in 2019/20.

We are particularly concerned by statements made by the CCG in the public arena about the effectiveness of IVF. Dr Sarah Whiteman, BLMK CCG chair, said: “It is the CCG that has to make the difficult decisions about what to commission based on evidence. Of course, it isn't just about the money, it's also about value for money and whether or not three [fertility] cycles offer that or not, for example. So it is a complex argument.”

We are sure the CCG is aware of the judgement in 2014 - Rose, R (on the application of) v Thanet Clinical Commissioning Group [2014] EWHC 1182 (Admin)- which made it clear that not agreeing with NICE guidance was not a reason for a CCG not to follow guidelines, and that a CCG is under an obligation in public law to have regard for the NICE guidance and to provide clear reasons for any general policy that does not follow it. Given that the CCG Chair has publicly questioned NICE’s decision-making regarding cost-effectiveness and evidence, we are concerned about the rationale for the proposal to cut IVF funding.

It is not clear why a decision was reached to offer only two possible proposals to the public. There was no option for funding two cycles. We would like to know why this was not offered as an alternative.

We are also concerned about the financial projections as figures are given as totals without detail as to how these figures have been reached. We know that where three full cycles of IVF are funded in Scotland, fewer than 10% of patients ever reach a third cycle. The CCG projects an increase of £774,845 on current fertility spending if two areas increased their IVF provision, which is almost double the current spending and seems a high projection.

The sharing of data, financial and capacity modelling work carried out by the CCG would be welcomed and should be a prerequisite of the process. We strongly urge the CCG to look carefully at NICE guidance and to establish a clear case which can be shared outlining the process and reasoning for any decisions, particularly decisions which do not follow the detailed advice of NICE on what is clinically and cost effective.

Bourn Hall
FERTILITY CLINIC

Submission to BLMK CCG on Specialist Fertility Treatment December 2021

What NICE say - Clear National Guidance

Dr Gill Leng, Deputy Chief Executive, NICE,

- "Infertility is a medical condition that can cause significant distress for those trying to have a baby. This distress can have a real impact on people's lives, potentially leading to depression and the break-down of relationships. However, in many cases infertility can be treated effectively - there are thousands of babies and happy parents thanks to NHS fertility treatment - which is why the NHS provides services and why NICE produces guidance on the topic.

NICE Recommended provision

- In women aged under 40 years who have not conceived after 2 years of regular unprotected intercourse offer **3 full cycles of IVF, with or without ICSI and up to 3 cycles of frozen embryo transfer**
  - If the woman reaches the age of 40 during treatment, complete the current full cycle but do not offer further full cycles.

- In women aged 40–42 years who have not conceived after 2 years of regular unprotected intercourse **offer 1 full cycle of IVF, with or without ICSI and 1 frozen embryo transfer**

What Bourn Hall says - View from the provider

Bourn Hall FERTILITY CLINIC

We believe to reduce the tertiary care element of this pathway would be a retrograde and discriminatory step which will leave a significant number of BLMK residents reduced likelihood of parenthood. We believe the likely impact of reduction of NHS entitlement will be an increase in cost to the NHS greater than any savings, as patients will seek low cost treatment abroad returning to NHS care with higher order multiple pregnancies and other complications of unregulated IVF.

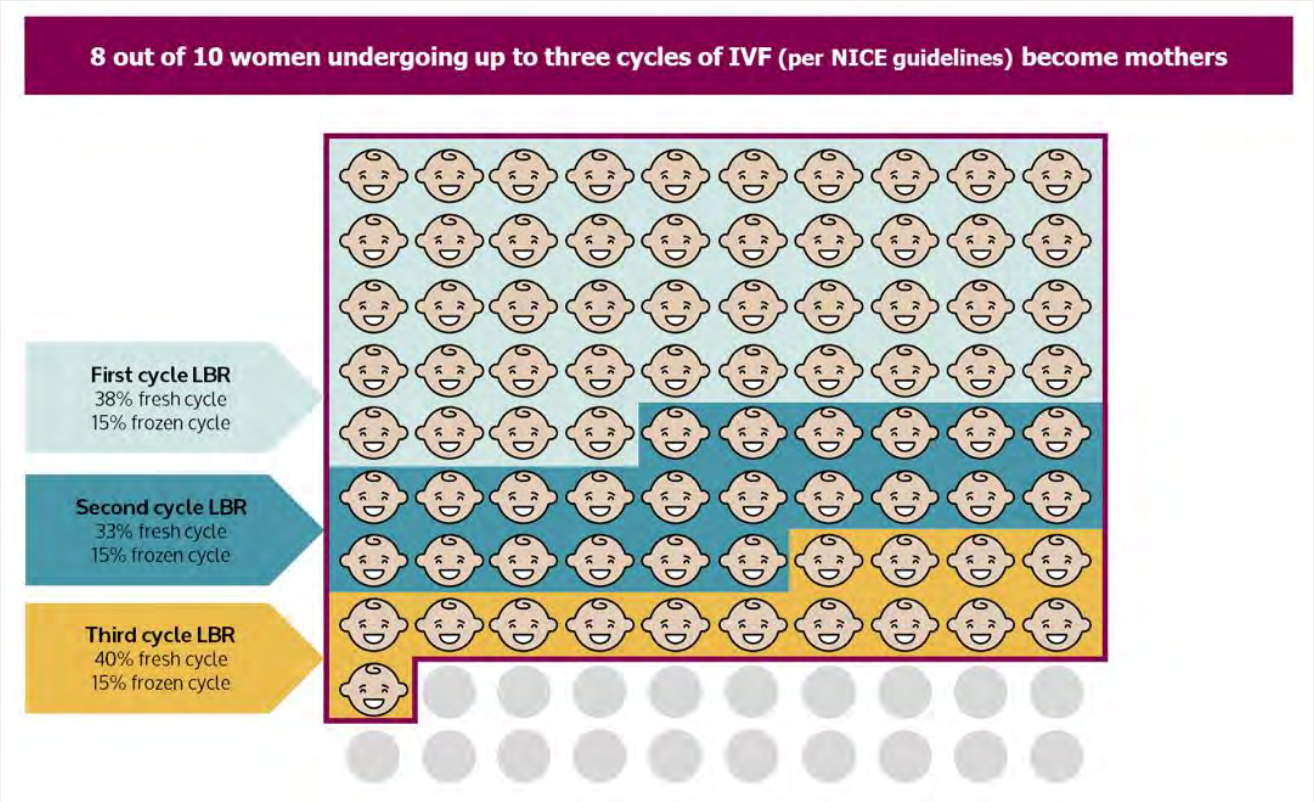
- Infertility is a painful medical condition affecting one in six couples
- Data shows that 40% of those with fertility problems suffer clinical depression and anxiety because of their inability to have children. Other studies show fertility patients have similar stress levels to those with cancer. Infertility is a “disease” and those afflicted need treatment.
- On average 600 couples per year are referred by the NHS to Bourn Hall
  - Close to 40% of these couples become parents on the first attempt and a further 35% on the second attempt – all singleton births
- Our single embryo transfer policy has minimised the likelihood of multiple births in these patients while maintaining world class success rates

- **Standards and Safety abroad**

  The level of legal or regulatory standards of clinics overseas varies greatly and not all countries have organisations equivalent to the HFEA. Some places have no specific laws or regulations relating to assisted reproductive services.
- Multiple births are 17 times more likely to be pre-term, requiring caesarean section and ongoing care due to complications
- A twin pregnancy costs at least six times more than a singleton and a triplet 18 times more for the delivery and first year of life

- See links here for report and data: http://www.irishtimes.com/opinion/why-fertility-treatment-deserves-state-funding-1.2355721

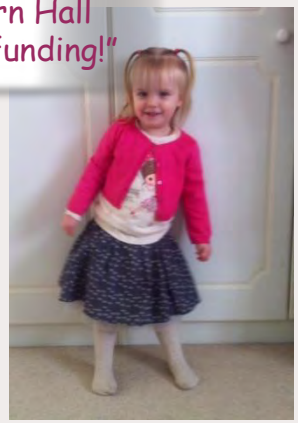
How many NHS patients became mothers?



- This Bourn Hall data demonstrates the likelihood of achieving parenthood by level of entitlement
- It is clear that parenthood is optimised by the provision of up to 3 fresh cycles of IVF
- **We encourage BLMK to *'level up'* the provision across the region**

"I don't think we will ever be able to thank Bourn Hall and the NHS enough."

"Our gorgeous little lady, age 2! Forever thankful to Bourn Hall Cambridge and to NHS funding!"



"My beautiful Bourn Hall miracle, Daisy. Thank you and thank you NHS a million times over!"

"Our Bourn Hall NHS funded miracle Henry. He is amazing and we are forever thankful."

"Our little Bourn Hall NHS funded miracle....every day she makes me smile, love her to the moon and back. Thank you so much."

"I cannot describe how important it was to me to receive NHS funding for my IVF treatment. Having Howie is absolutely worth it."

Bedfordshire Local Pharmaceutical Committee
Representing Community Pharmacies in Bedford Borough, Central Bedfordshire and Luton

Enterprise House, Wrest Park, Silsoe, Bedfordshire, MK45 4HR
Mobile: 07800 764717 Email: info@bedslpc.org.uk

Chief Officer	Chair	Vice Chair	Treasurer
Gerald Zeidman FRPharmS	Coll Michaels	Nishil Shah	Paul Fearon

19th December 2021

To Whom It May Concern,

BedsLPC have the following comments to make regarding the public Consultation to align Policies across Milton Keynes, Bedfordshire and Luton.

Fertility Services
No comments to make

Gluten Free Food Prescribing

- Gluten Free prescribing should be aligned across BLMK
- We agree that the provision of Gluten Free bread and flour within the NHS, for those at risk of dietary neglect should continue, where medically appropriate

Milton Keynes Pharmacy First Minor Ailments scheme

- It is noted that this scheme is not available for patients in Bedfordshire and Luton and that an equitable scheme should be available to everyone across BLMK
- Patients referred to community pharmacy via the 111 CPCS service are required to pay for any over the counter medication recommended by the pharmacy. This may discourage patients from accessing CPCS and with restricted GP access could affect patient care.
- BedsLPC recommends that if the MK Pharmacy First scheme is discontinued, the current spend of £25,011 is redirected into the provision of either over the counter medicines, where appropriate or prescription only medications supplied by the pharmacy under a PGD. This may help to avoid patients needing to be referred by the pharmacy to their GP or an out of hours service
- Any savings resulting from the Case for Change relating to community pharmacy should be redirected into new community pharmacy initiatives for the benefit of patients

We trust that our comments are helpful. Should you requires further explanation for the points raised please contact us via the phone & email above.

Virtual Public Engagement Sessions

We would like to thank those members of the public who attended the engagement sessions. They gave freely of their time and shared in great detail their experience of fertility services and the impact these services have had and continue to have on them.

21 October 2021

We held an online patient drop-in session on 21 October 2021 from 6pm-7.30pm, a single sex couple attended with interest in Fertility Services.

General Comments

As a same sex female couple, we went into fertility services thinking that we would go through a few rounds of IUI before becoming pregnant. As we have gone through, we have realised that is not the case, we needed a clear plan from our provider of when to stop one form of treatment and when to go onto the next treatment as there is so much information and its over whelming when you have not had experience of fertility services.

Will the policy for same sex couples include shared mothership? Where eggs from either partner can be used, rather than where only the eggs from the 'carrier' are used.

Donor Sperm

Will the policy include the cost of donor sperm, we have been paying £1000 for the donor and then shipping costs in addition to that.

When donor sperm becomes too expensive it drives people underground, we are trying to stay within the HFEA regulations and guidance, but a lot of same sex couples are contacting sperm donors on Facebook. In this scenario there is not medical history of the donor and it is completely unregulated, but some couples see it as their only option currently.

Private Treatment

Having been through IUI unsuccessfully we have moved onto private IVF. Within the private sector, we felt that on each round of IVF we were offered something extra to improve the chances of success.

If you are only going to offer one attempt of IVF, then that attempt needs to be the best attempt and consider the risk rating of embryos to ensure the best quality embryos are used. We paid extra for CAREmaps and blastocyst transfer to gives us the best chance of a successful cycle.

During our treatment we would be sitting in a waiting room, and we have paid £8000 to be there and others are getting treatment free on the NHS, purely because we are a same sex couple. We pay national insurance the same as everyone and that is where the system is flawed.

To go through 12 rounds of treatment, depending on treatment it will cost between £48,000 - £112,000 privately, this has been the only option for same sex couples living in areas where treatment is not available on the NHS. When we tell people we are not eligible for treatment as a same sex couple they are shocked and assume that we would be.

IUI and IVF Cycles

It would take around 1 ½ years to complete 6 rounds of IUI. In the new policy the proposal is to include 6 IUI's for same sex couples before moving onto IVF, this would be fully funded NHS treatment within the policy.

We were told you can give 10 women the same treatment/protocol and each of them will respond differently to it. Offering one cycle of IVF, does not take into account these variable factors. We have done everything asked of us to keep healthy and do everything for an optimum cycle and unfortunately our first round just was not successful. One size does not fit all.

Before we started our first IUI we had a HyCoSy to check that IUI was a viable option for us, will this be included in the policy?

Within a same sex couple, if the policy is that just one partner can have access to fertility treatment, will investigations be available for a both before a decision is taken as to which partner goes forward to have the treatment?

Cost of Medication for IUI and IVF

A lot of clinics have their own pharmacy – the mark up on the medication from them is huge.

We are buying the same medication from a different clinic who have a partner pharmacy who don't put a mark-up on the medication but do have £75 fee and £30 postage (as is on ice) – this still costs us half of what we were paying from a different clinic.

One area to review would be the pharmaceutical contracts for the required medication as this could help bring costs down for treatment.

30 November 2021

We held an online patient drop-in session on 30 November 2021 from 6pm-7.30pm, two members of the public attended, their interest in the policy alignment consultation was in the Fertility Services aspect. Three people had registered for the event who indicated that their interest was in gluten-free food on prescription and Milton Keynes Pharmacy First scheme, however none of those registered with that interest attended the event.

General Comments

It's good that the policy is being extended and is going to be more inclusive, but why is the policy looking to level down and not up and therefore not in line with NICE guidance.

If the issue is about equality and not budget then the access to services should be levelled up to three cycles across BLMK.

If egg collection and embryo transfer is outsourced to private clinics, what work has been done with those providers to ensure best value is being achieved.

Has mild IVF been considered where appropriate as a treatment to be tried before IVF?

Key Themes

Impact on Mental Health

The effect on patient's mental health cannot be underestimated, the entire life experience of infertility is hugely distressing.

Fertility Network UK survey indicated that 90% of those experiencing infertility suffer from depression and nearly half of those consider suicide. Reducing the fertility services available will trigger mental health issues. This has a financial impact on the NHS.

For people suffering with infertility, if they don't access support from national charities there is nowhere for them to go, and many do not feel they can talk with friends and families about infertility.

One patient attending had one unsuccessful cycle of IVF on the NHS and had suicidal thoughts. They commented that not everyone can afford to have private treatment, they were offered a transfer of five embryos at a clinic in Turkey, but decided against it.

Nine and ½ months, after a decision is made to reduce the number of cycles maternity costs will go up and within a few weeks of the decision Mental Health support costs will go up. It's a shame that the different costs are in different columns on the spreadsheet because if you could see the impact across services it would be clear.

Accessing Fertility Services outside of the UK

When services are not available to patients, this leads to some seeking cheaper services outside of the UK. That means that the services that people access are not regulated by the Human Fertilisation and Embryology Authority (HFEA) who limit the number of embryos that are allowed to be transferred in one cycle.

When people are desperate if a clinic outside of the UK says they will transfer multiple embryos if they are viable, couples will go for this option. This increases the risk of patients returning to the UK pregnant with twins, triplets quads and potentially even higher.

This needs to be considered due to the higher costs for the NHS in providing maternity and post-birth services to these families, there are also health risks associated with multiple births.

It’s hard to articulate the desperation that couples feel when they don’t have the privilege to conceive naturally. There is nothing that anyone in this country could have said to us that would have stopped us travelling abroad for treatment if it was our only option. We would have been willing to take the risk.

The feeling of not being able to conceive naturally and the uncertainty that brings every day and night of your life, not knowing if it will happen for you, is the most overwhelming thing.

Q6 Would you like to comment on any of the other eligibility criteria for Fertility Services?

Q6: Access criteria (general comments)
Fertility should be accessible for all within a certain criteria ie age weight etc people need this option as private ivf is too expensive for most
Fertility treatment really matters for us that has medical issues. I have been told that I will have to have IVF. I would prefer 3 tries rather than the 1 as it would give me a better chance of conceiving.
Good to see your extended access criteria - well done
Having Turners Syndrome and unable to have children due to chromosome defect. I feel that affordable options are limited to individual with rare conditions at no fault of their own . I would like clear guidelines and criteria for couples .
If these services are cut we cannot afford to pay ourselves. I am a teacher who gives a lot to society and deserve a good chance in fertility.
IVF should not be available on the NHS to any individual or couple who have not attempted to conceive naturally over a period of at least a year. There is a vast difference between those who cannot conceive despite trying and those choosing not to conceive through natural methods due to sexual or other preference. Whilst all those who seek to be loving parents should have this opportunity, alternative options such as adoption are more appropriate where conception is not possible due to choice.
Make treatment for a second child available if IVF is the ONLY option, eg tubal factor where there is 0% chance of conceiving naturally
More people should be allowed access to this treatment.
The policy should apply to all people wanting fertility help.
Uk resident for at least 3 years prior to treatment
Under 30's should be allowed unlimited attempts
Under equality laws, should gay male couples/single men be allowed to access IVF with a surrogate?
Q6: Age limit
- the removal of an upper age limit for the sperm provider in IVF is potentially questionable. Studies link advanced paternal age to autism and other issues in the child, as well as lower semen quality parameters. Perhaps this warrants further research and discussion. See the HFEA's policy on sperm donors (max age 45 unless extenuating circumstance)
Age should be extended for those that do not have a first child.
At present in Bedford we can only access 1 cycle of IVF and only up to the age of 40. It would be helpful this could be increased to age 42 in light of the fact we are all living longer, we are starting families later for financial and societal reasons. Ideally it would be helpful for the 39 and unders to have access to 3 cycles. But as a minimum it makes sense for women up to 42 to have access to IVF
In addition to the tragedy of this at a personal level, it is relevant to cost effectiveness assessments, since poor outcomes linked to multiple births are costly for the NHS to address later. BLMK should increase the number of cycles in Bedfordshire and Milton Keynes to three cycles for all patients aged 39 and under, and one cycle for all eligible patients aged 40-42, in line with the current Luton model.
Fertility should be accessible for all within a certain criteria ie age weight etc people need this option as private ivf is too expensive for most
I would like to see ladies 40+ eligible for the same cycles as 40 and younger Ideally three as in Luton
option 2 discriminates older mums who live with fertility issues,
Option 2 should be available to all aged under 42
Paternal age - isn't this a risk factor in relation to genetic abnormalities? Maybe maintain current paternal age upper limit Agree changes re extending to other groups i.e.same sex couples makes sense/is fair
Should it not be the same offer for women of all ages?
The limit of age should increase too

The NICE guidelines state If you are a woman aged under 40 you should be offered 3 full cycles of IVF. Infertility is a medical condition and can effect peoples mental health. Not everyone can afford private health and it should not be a postcode lottery.
The three cycles should be available until age 42. The restrictions cutting off at age 39 for 3 cycles can be daunting, some may have multiple reasons and already be in the 40s age groups and may not be able to fund future treatments. It is unfair to limit woman who also may settle down later in life and start a family. This can lead to mental trauma being unable to naturally conceive, being 40+ and having just one chance to being a parent. This can raise more mental health issues with the stigma and social anxities of not being a parent.
Women aged 40-42 should also be offered 3 cycles given their success rates are lower and they are likely to be in greater need of more cycles. Please done not underestimate the affect that not funding fertility treatment has on patients mental health which she be considered as important as physical health. Not only this, infertility is a disease as recognised by who. Treatment for other diseases would not be limited to a certain number of attempts, fertility treatment shouldn't be either.
Would be lovely if the service could be extended to those who missed out over 40. I was 27 at the time of my third ivf cycle qualifying for nhs ivf. However that very month, the nhs canned all ivf options in Cambridge. Tragic. Now they've reinstated one but I'm 42 :(soo unfair to not have had the chance at all.
Q6: All women should have the right to have a baby
Any female should be given the opportunity to have a baby, whether that be naturally or with some medical assistance. Some women feel they haven't become a woman until they have had a child and why should this be denied to them? There are hundreds of women who are not able to conceive naturally through no fault of their own, why should they be penalised for this? There are so many women that access health services to terminate a pregnancy so the same availability should be given to those who want to conceive a baby as well
I feel strongly that all women should have the ability to be mothers, if having two rounds of IVF can help then we should not be stopped.
We should all have equal opportunities to have our own baby and experience that bound and love.
Q6 AMH and FSH
Accept AMH as well as FSH
AMH should be considered as well as/instead of FSH blood results as these are more reliable
Considering AMH results as well as women's FSH blood test results as many other CCGs do
Higher the FSH eligibility to >9 and/or consider AMH blood test results
I believe that the fsh cut off is an outdated way of measuring ovarian reserve and should now be AMH instead
Increase the FSH score cut off
To accept AMH as well as FSH
Use AMH as criteria for ovarian reserve
Q6 References to 'any person with a uterus'/transgender/non-binary
BPAS Fertility are pleased to see BLMK proposing that fertility services policy entry point be broadened to provide access to specialist fertility services for same sex female couples, single females and any person with a uterus (including trans men and non-binary people) and that these patients will be entitled to NHS funded IVF treatment following 6 cycles of NHS funded donor IUI.
Fertility services should be restricted to women born as women.
Hermafroditas should also be mentioned in the groups to make sure people understand they are eligible
I am totally disgusted by the wording of this document, is discriminatory, insensitive, hurtful & ignorant and I wish it to be withdrawn & amended immediately. My daughter who is currently having IVF (infunded) does not have a uterus as many many other women in this country also do not your phrase 'anyone with a uterus ' is quite unbelievable that the NHS Ccg have such little understanding of infertility & although seeking to be inclusive have actually done the complete opposite
I do not believe that ivf should be offered to trans men and non binary
I find that I disagree with inclusiveness of Trans men and this in itself does not promote inclusiveness since other trans who may or may not originally have had a uterus are not able to receive such treatment. Additionally

identifying as a man surely does not include giving birth? Maybe I'm outdated in my thoughts. But I am pro trans in many ways but I feel fairly so.
It is a shame there is no option 3, where luton goes down to 2, Bedfordshire and MK go up to 2 and the service is extended to same sex female couples and any person with a uterus.
Should not be given to trans people.
There is absolutely no way these options shouldn't be available to LGBTQ+ people but one course is not acceptable . For most people, cisgender or otherwise, it takes more than one cycle and there is no way we should deny children to anyone in our area
There should be three rounds offered for those requiring ivf nhs treatment for all residents in Luton, regardless of female, in single sex relationships, or bi gender.
Your woke shit will be your downfall. People are getting sick of it. "People with uterus..."
Q6 Children from other relationships
Allow childless women who's partners have a child from a previous relationship to access IVF NHS treatment
Any children a male partner has had in the past should not affect a woman's eligibility to receive fertility treatment
As a person who tried to access ivf at a much younger age to be told no as my husband had fathered a child therefore not eligible it took me 5 years to work the finance es to go for private route. As each year passed my biological clock worked against Me. I am now over 40 & pregnant luckily on my first cycle which cost £20,000. This would of been worse if the cycle didn't work. I have friends in diff ccgs and given the opportunity of 3 rounds free. Just sad I was not given the opportunity.
The proposed BLMK policy on known parental status would make couples ineligible for treatment if there are any living children from the current or any previous relationships who they have contact with, this presents a significant barrier to care for many patients. Access to treatment should be based on clinical need, not judged on the basis of such things as past relationships. The existence of living children should not be a factor that precludes the provision of fertility treatment. BPAS Fertility recognise the funding pressures CCGs face when making resource decisions and we are also working at a national level to highlight and address the systemic problem with the way fertility services are funded in England.
Clarification is required on the following points: Known parental status- revision states will not meet criteria if there is a 'child' from either side who they have 'contact with'. This is really open to interpretation. Are you referring to having contact with a child under 18? If existing child is over 18 does having contact with them count? Does contact mean physical contact i.e regular visits or does digital contact count (especially in post COVID world). Would the 'child' have to be residing in the UK or could they be abroad (and having occasional 'visits'. How could it be proven that a couple does not have contact with a child? who would be checking? If a couple are 'savvy' and have read the policy, they would know what to say on this in order to meet criteria on this point and so there could be inequity. I personally feel that if one of a couple has had a child from a previous relationship, this should not be a factor to a newly formed couple wanting to start a family of their own and if there are fertility problems for that 'couple', they as a unit should be able to access fertility services. The
In addition, those who have a child through a previous relationship should also be included, as it often unfairly penalises one person within the relationship.
If your partner has a child from a previous relationship you should still be entitled to Ivf
It is not fair that partners with children from previous relationships are not eligible for IVF. Whoever created this awful rule has clearly never longed for children and experienced fertility issues
NICE guidelines should be followed to fund fertility treatment for couples where one partner has a child from a previous relationship. In no other field of medicine am I discriminated against for treatment of a disease (infertility is recognised as a disease by the WHO) because my partner accidentally had a child 12 years ago… It is also ridiculous that this is a post code lottery
Parents who have children from previous relationships should be excluded in order to give as many people as possible the chance to become a parent. Funding should not be given where people already have children but are unable to do so with their current partner.
Services should not be refused for women who have partners with children from other relationships. This is very unfair as the woman seeking treatment misses out through no fault of her own.

Partner's other children should not be a factor.
Q6 Funding
costs too much, scrap it. it is not essential.
Funds could be better spent elsewhere.
I don't think BLMK CCG should do either option 1 or 2 because of the cost
I think this is something people should fund for themselves. It is hardly a medical necessity.
Neither option. In view of the cost to the economy of Covid19, I would prefer the minimum national option.
NHS is in place for health care services. Same sex couples do not necessarily have medical issues which prevent successful fertilisation. Money spent on this could be used for actual health complaints like reducing waiting times for surgery.
No IVF should be funded at all, for anyone, unless infertility was the outcome of an illness (eg cancer treatment) or injury. Why is this not an option being considered?
Proper cost-benefit analysis should be carried out for each service offered
Q6 Inequality in Local Authorities
As a commissioning body you have unfairly allocated budgets for fertility treatments, Milton Keynes is expanding rapidly, to limit patients to one opportunity which we know oh to well does not always work, patients should be given the right to a fair chance at conception, one chance is not fair. Three would be. I guess you run the demand and capacity on Luton's data to understand what percentage of patients are successful on their first go to attain if that 1 try option that you prefer will work. Doubtful, I suspect many people will then go on to years of financial torment without the option of a 2nd or 3rd go.
Statistics show that very few parents are successful in one cycle. Three must be offered to give them the best chance. There should be levelling up across the CCG not levelling down.
Having the opportunity to have 3 IVF cycles on the NHS is an incredible opportunity to have and should be offered to all areas.
I believe that option 2 is the most suitable and fair. The NICE clinical guidance (CG156) states that women should receive 3 cycles of IVF (1.11.1.3). To deny this is hugely stressful and upsetting to individuals/couples/families going through what is already one of the most difficult things that many people will experience. I hope, wholeheartedly, that option 2 will be adopted through BLMK, to provide hope to women facing infertility.
I think decreasing a service offered in Luton to align with others would be devastating to couples and individuals trying to conceive through IVF. People deserve the right to have a child as a natural progression in life without the burden of people able to afford just to conceive.
I think that the criteria should be increased to allow more people access to fertility services and to align with what is currently offered in Luton
It is a shame there is no option 3, where luton goes down to 2, Bedfordshire and MK go up to 2 and the service is extended to same sex female couples and any person with a uterus.
The fact it's not 3 across all is an absolute joke. And Milton Keynes and Bedford CCGs should be ashamed
The NICE guidelines state If you are a woman aged under 40 you should be offered 3 full cycles of IVF. Infertility is a medical condition and can effect peoples mental health. Not everyone can afford private health and it should not be a postcode lottery.
To make is fair across the area it should be two in all areas which is a balanced use of resources.
Q6 Multiple embryo transfers
BLMK CCG is proposing to implement the number of embryo transfers in line with the number of cycles agreed as per the outcome of this consultation. e.g. 1 cycle offered = 2 embryo transfers (1 fresh and 1 frozen). 3 cycles offered = 6 embryo transfers (3 fresh and 3 frozen). NICE defines a full cycle of IVF treatment as "1 episode of ovarian stimulation and the transfer of any resultant fresh and frozen embryo(s)" (NICE, 2013). This suggests that all embryos of suitable quality created from each IVF cycle should be available for use until an embryo transfer is successful in achieving a live birth or until no embryos remain. The availability of multiple embryo transfers per cycle is important in order to remove the incentive to transfer several embryos at once, which slightly increases the chance of a pregnancy but also leads to multiple births – the biggest health risk to both mothers and babies from IVF (HFEA, 2020). The availability of multiple embryo transfers within a cycle also reduces the chance that women will

have to undergo a subsequent full cycle of IVF to achieve a pregnancy, reducing their risk of ovarian hyperstimulation syndrome (OHSS) (HFEA, 2020; Smith et al., 2015). The number of embryo transfers per cycle should not be limited, instead all stored and viable embryos should be used in a cycle.
The other confusing criteria was embryo transfers. It's not clear to me whether the CCG is describing in amended criteria the number of embryos transferred 'at a time' or whether its describing the total number of embryos used. It would seem to be stating for Beds/MK this would be 2 but if went with the Luton model it would be 6? However, in the glossary it then describes that a full cycle is when all the via embryo's have been used. Theoretically, if there was 6 viable embryo's then 2 would be used straight away and then the following 4 frozen would be used via 2 attempts to complete a full cycle??? sorry its just not clear
Why is one cycle only 2 transfers? If you are considering reducing everyone down to just 1 cycle, couldn't you allow for transfer of all viable frozen embryos that were taken in the cycle rather than just 1 fresh and 1 frozen?
If CCG selects option 1 then provide up to three single embryo transfers.
Q6 Number of IVF cycles
1 cycle isn't very much chance of conceiving vs 3. Unfair it's not aligned across the CCG
As a commissioning body you have unfairly allocated budgets for fertility treatments, Milton Keynes is expanding rapidly, to limit patients to one opportunity which we know oh to well does not always work, patients should be given the right to a fair chance at conception, one chance is not fair. Three would be. I guess you run the demand and capacity on Luton's data to understand what percentage of patients are successful on their first go to attain if that 1 try option that you prefer will work. Doubtful, I suspect many people will then go on to years of financial torment without the option of a 2nd or 3rd go.
As an individual living in Luton who underwent 3 IVF cycles on the NHS before finally successfully giving birth on the final NHS cycle, I cannot over emphasize the need to retain the provision of 3 cycles to eligible individuals and to extend the offer of 3 cycles to those in other areas of Bedfordshire, as is recommended by NICE guidelines. IVF is not a precise 'one fits all' process, and the option of having 3 cycles allows the clinical team to tailor the IVF process to the individual based on their expertise, for instance by trying different protocols and varying the dosage of medications in order to optimise success. Every woman is different, and responds differently to IVF, and the ability for the clinical team to learn so much from a failed cycle and improve on it in the next cycle by tweaking the protocol is essential in achieving a successful outcome, as was my experience. I also believe the number of cycles offered to eligible patients aged 40-42 should either be increased from 1 cycle to 3 cycles, or alternatively there should be an option to make it more accessible to people in this age bracket, for instance, the patient covers half the cost and the NHS the other half.
However, it is disappointing that BLMK CCG would prefer to reduce the current offer of three cycles of IVF to residents in Luton to one cycle for all eligible patients, such a measure will inevitably reduce patients' chances of achieving a successful pregnancy. Whilst we appreciate the intense funding pressures CCGs are under and the difficult job of allocating resources to address competing health needs, to reduce the number of cycles offered to one would likely impact cost effectiveness: in its Quality Standard 73, NICE states that offering fewer than three cycles is unlikely to be cost effective based on a live birth rate per cycle of 28% (NICE, 2014e). The withholding of fertility services has real consequences, both for patients and the health service. Infertility is recognised as a medical condition by the World Health Organisation, and it is known to cause psychological harm for many of the people affected (WHO, 2016; Kmietowicz, 2012). Many patients who are unable to access fertility care on the NHS are known to travel abroad for care.
In addition to the tragedy of this at a personal level, it is relevant to cost effectiveness assessments, since poor outcomes linked to multiple births are costly for the NHS to address later. BLMK should increase the number of cycles in Bedfordshire and Milton Keynes to three cycles for all patients aged 39 and under, and one cycle for all eligible patients aged 40-42, in line with the current Luton model.
Could it be extended to two attempts instead of one? I don't think one cycle is enough and probably causes more stress because there is only one chance. I think 2 attempts is the most fair. I still believe that having a loving Mum and a Dad is the best thing for a child. As a single women, I have thought of IVF, but this belief has always made me hesitant.
everyone should be entitled to 3 cycles - imagine if you were only given one chance. even if it was successful, you would only have 1 or 2 babies.

Everyone should have access to at least 3 cycles regardless of any criteria, gender, age etc
Fertility treatment really matters for us that has medical issues. I have been told that I will have to have IVF. I would prefer 3 tries rather than the 1 as it would give me a better chance of conceiving.
Statistics show that very few parents are successful in one cycle. Three must be offered to give them the best chance. There should be levelling up across the CCG not levelling down.
Having the opportunity to have 3 IVF cycles on the NHS is an incredible opportunity to have and should be offered to all areas.
I believe that option 2 is the most suitable and fair. The NICE clinical guidance (CG156) states that women should receive 3 cycles of IVF (1.11.1.3). To deny this is hugely stressful and upsetting to individuals/couples/families going through what is already one of the most difficult things that many people will experience. I hope, wholeheartedly, that option 2 will be adopted through BLMK, to provide hope to women facing infertility.
I feel strongly that all women should have the ability to be mothers, if having two rounds of IVF can help then we should not be stopped.
I feel women are discriminated against as they are limited to one cycle. A male partner though can move onto another relationship and have more cycles. This kind of discrimination should not exist in this day and age
I strongly believe that the number of cycles needs to increase, as the probability of fertilisation after one round of IVF is limited. This is often a life changing decision and those without means to financially support it outside of the NHS can be severely impacted
I would like to see ladies 40+ eligible for the same cycles as 40 and younger Ideally three as in Luton
If option two is not cost effective then at least offer two cycles per couple. The chances of one cycle working are incredibly slim
It would be unfair to cut the amount of cycles to 1 and take away the hope couples have to having a baby in the future
More people should be allowed access to this treatment.
NICE guidance is based on what is clinically and cost effective. There is no reason not to follow this locally. There is no explanations of your cost projections or of how these were reached which is extremely poor. You have not consulted before offering these options to the public which is also very poor. Are you going to be offering full cycles? Why did you decide not to give people the option to suggest two cycles? On what basis did you decide to give these two options only? Infertility is defined by the WHO as a disease and NICE has judged IVF to be a cost effective treatment for this, based on the provision of three full cycles. Unless you have evidence to the contrary, you should be following NICE guidance.
NICE guidelines recommended 3 cycles to give the best chance of one live birth. IVF is treatment of a soul crushing condition that impacts mental well-being, please give it the importance it deserves.
NICE guidelines state that all should have access to 3 fully funded rounds. It is unthinkable that a commission should decide that anyone deserves less than this. People going through IVF have already suffered significant trauma in their lives, they deserve every opportunity to have a child of their own.
None of the above. Support an increase in available cycles to those that are eligible to three as in Luton.
One cycle often doesn't help anyone. It can make the stress much worse for those going through it (which in turn won't help the outcome) as it's 'our only chance'. If after 3 cycles it hasn't worked, people may be more open to the acceptance that maybe it just can't happen. Plus it will give them time to save to pay for a 4th attempt if need be.
One round of IVF simply isn't enough. The success statistics on 1 round show that it's quite unlikely to fall pregnant with your first IVF round. I am 32 and have already had 2 failed IVF rounds
So many time people can't afford IVF and 1 cycle only offers some percentage of success depending on the patients condition. Multiple cycles offer bigger chance.
The NICE guidelines state women should be offered 3 full cycles of ART treatment as the cumulative effect of the 3 cycles increases the chance of success of treatment & live births.
This service could be a lifeline for many. Please keep it to 3 cycles.
We actually have a declining population and an ageing one. It's unusual for IVF to be successful first time so women need a decent chance.

We conveniently got delayed in the system whilst trying to qualify for IVF on the NHS in that time the number of rounds changed from 3 to 1 without out knowledge.
You should not be reducing this! Sometimes it takes more than one cycle! Not everyone is lucky enough to conceive on the first try!!!!
Q6 Priority to those with no existing children
I think people that have had a child successfully should be lower down the priority list than those who have never managed to have a successful pregnancy
Make treatment for a second child available if IVF is the ONLY option, eg tubal factor where there is 0% chance of conceiving naturally
Perhaps consider restricting it to people who do not have a child already so as to prioritise people who have none
Priority to those without Children
Whilst not in the case for change , priority should be given to couples without any children
Q6 Same-sex couples
the inclusion of same sex female couples/single women and the allowance of immediate access to NHS funded IVF is a fantastic and progressive policy suggestion which I fully support.
BPAS Fertility are pleased to see BLMK proposing that fertility services policy entry point be broadened to provide access to specialist fertility services for same sex female couples, single females and any person with a uterus (including trans men and non-binary people) and that these patients will be entitled to NHS funded IVF treatment following 6 cycles of NHS funded donor IUI.
Do not believe fertility treatment should be given to same sex or single women. Only those with a medical reason they need treatment. Single women is a choice not a medical reason. Same sex couples is not a medical reason.
Everyone with fertility difficulties regardless of sexual orientation should have access to 3 rounds of IVF
I am shocked to hear some of the exclusions for IVF including same sex couples. Time to modernise and get in step with current contemporary views of the public
I dont think it should be offered to same sex couples.
I feel this is extremely important for same sex couples the deserve a chance at a family
I think all same sex couples should have the same rights to fertility treatment as heterosexual couples.
It is a shame there is no option 3, where luton goes down to 2, Bedfordshire and MK go up to 2 and the service is extended to same sex female couples and any person with a uterus.
NHS is in place for health care services. Same sex couples do not necessarily have medical issues which prevent successful fertilisation. Money spent on this could be used for actual health complaints like reducing waiting times for surgery.
Same sex couples seem to be discriminated against when having to go 12 failed rounds at considerable cost to themselves when heterosexual couples only have to have 3 failed attempts.
Same sex couples should not be eligible.
Same sex couple have the opportunity to undergo 3 attempts at IUI prior to commencing IVF whereas not all heterosexual couples are offered IUI prior to IVF so it is unfair for them to be disadvantaged & their number of cycles reduced.
There is absolutely no way these options shouldn't be available to LGBTQ+ people but one course is not acceptable . For most people, cisgender or otherwise, it takes more than one cycle and there is no way we should deny children to anyone in our area
There should be three rounds offered for those requiring ivf nhs treatment for all residents in Luton, regardless of female, in single sex relationships, or bi gender.
Under equality laws, should gay male couples/single men be allowed to access IVF with a surrogate?
Q6 Single women
the inclusion of same sex female couples/single women and the allowance of immediate access to NHS funded IVF is a fantastic and progressive policy suggestion which I fully support.
As a single female wanting to conceive via a donor I feel that whatever option is chosen the services should not discriminate against single women as there are many physical and mental reasons why the choice is made to use a donor and we should have access to safe methods of Conceptiom

BPAS Fertility are pleased to see BLMK proposing that fertility services policy entry point be broadened to provide access to specialist fertility services for same sex female couples, single females and any person with a uterus (including trans men and non-binary people) and that these patients will be entitled to NHS funded IVF treatment following 6 cycles of NHS funded donor IUI.
Do not believe fertility treatment should be given to same sex or single women. Only those with a medical reason they need treatment. Single women is a choice not a medical reason. Same sex couples is not a medical reason.
I believe single women should have access to IVF much easier
There should be three rounds offered for those requiring ivf nhs treatment for all residents in Luton, regardless of female, in single sex relationships, or bi gender.
Q6 Waiting time for IVF
the inclusion of same sex female couples/single women and the allowance of immediate access to NHS funded IVF is a fantastic and progressive policy suggestion which I fully support.
I think the length of time that people should have to wait to start fertility treatment should be reduced to 2 years based on the data of how many woman would actually get pregnant naturally after this point. Some women are also having children late Rin life due to a variety of factors and women don't know they are going to have fertility issues until they start trying. Asking them to wait 3 years and then the possible delays of actually being referred/ starting treatment could be too late.
Unexplained infertility to have more focus, not the current three year wait for help. Mental health and physical well-being takes its toll in this time.
Q6 Weight and BMI
BMI criteria (30) is too unrealistic for some people and being prevented from accessing treatment is causing eating disorders and mental health issues. There is no research to prove treatment cannot be effective at higher BMI thresholds, people should have the same access and have the choice to lose weight first or go ahead with treatment. Other countries do not have any criteria on weight, people in the UK are forced to go abroad, this affects people's human right to a family life. The criteri should at the very least be changed to be the same as for private treatment (35) otherwise this policy discriminates against those who cannot afford to have private treatment. If you are reviewing availability of treatment, please also address these significant access issues - happy to discuss further
Bmi is outdated and should no longer be used
Change the BMI requirements before IVF - if a prospective parent can prove they're eating well, exercising regularly, reduced alcohol intake etc, this shouldn't affect their chances of getting help. Women with PCOS, endometriosis and similar hormonal conditions find it difficult to lose enough weight to get to or under the required maximum BMI
Eligibility for those with high BMI should be in line with others
Fertility should be accessible for all within a certain criteria ie age weight etc people need this option as private ivf is too expensive for most
I have been denied fertility treatment for the last 3 years due to my BMI. I have PCOS and find it near impossible to lose weight. I also live a healthy lifestyle, have an active job, eat well and have a personal trainer. I am stuck in a very sad place of being denied treatment on the NHS, but can't afford private treatment. This rule desperately needs to change.
It is vitally important that the local guidelines/implementation of guidelines in relation to patient BMI. I have been denied all options, even basic treatments (e.g ovulation boosting medication), due to having a BMI over a certain threshold. Nowhere in the NICE guidelines does it say that BMI should be used as an exclusion criteria but that is exactly what is happening. It is not evidence based and it is discriminatory. When I have challenged my treatment decisions, I have been told it is due to 'the guidelines' but there is no guideline I have read that advises this so I have to conclude it is local policy. Please review this in favour of a more evidence-based approach that looks at actual measures of health and actual patient outcomes.
Outdated BMI information shouldn’t be a stead fast rule. I’ve seen those seeking fertility treatments on the nhs use drastic and unhealthy ways to loose weight for weigh ins.

Please also offer support to women that struggle to lose weight to meet the BMI requirements set out. Obesity is a country healthy issue and therefore should be dealt with properly. Simply striking out obese patients from the criteria will not help. A lot of patients with proper care and follow up would be able to bring down the weight to proper levels, but leaving eager wannabe mothers just "abandoned" to lose weight by themselves will only create malnutrition and poor health before the treatment even starts, slimming the chances of successful outcomes.
Review the BMI criteria…..I nearly gave in to an eating disorder because of it despite working out 5 times a week and eating right because I was building muscle and loosing inches that wasn't good enough and although my internal health was better than ever just because my 'scale weight' wasn't right I was deemed fat and unhealthy which was far from the truth, I was given no help with loosing weight even with PCOS just 'eat less' and exercise (which I was doing) BMI is outdated and harmful
Should a person's health not be a more important criteria than bmi
The outdated and discriminatory measure that is BMI should not be a factor.
This should include folks with all BMIs. Fertility support should not be discriminatory and that must include folks at higher weights too
Those with high BMI should be allowed to access their human right to reproduce. Although some risks during pregnancy increase, these are relative increases, not dramatic, and are for the patient to make informed choices around, not to be given no choice. Research and scientific studies are being reviewed and updated on this. An expert in this area is Nicola Salmon, of Fat Positive Fertility.
Up to date on restrictions due to weight.
Q6 Other
(NB sometimes these comments are duplicated elsewhere, if part of the comment falls into another category; they have been placed here because another part of the comment cannot be placed under a main category)
- the final point of the appendix is confusing. If one partner in a same sex female couple used only one round of IVF, would the other partner be allowed to then access two rounds (if there is a three round maximum)?
As a person who tried to access ivf at a much younger age to be told no as my husband had fathered a child therefore not eligible it took me 5 years to work the finance es to go for private route. As each year passed my biological clock worked against Me. I am now over 40 & pregnant luckily on my first cycle which cost £20,000. This would of been worse if the cycle didn't work. I have friends in diff ccgs and given the opportunity of 3 rounds free. Just sad I was not given the opportunity.
For our economy to work we must have successful demographics in an ageing population. The birth rate is falling. Many more young women and men are having difficulty conceiving, especially those who have started late or missed diagnosis earlier. Statistics show that very few parents are successful in one cycle.
Fertility is wrongly regarded as a 'nice to have' rather than a health need. It is also wrongly regarded as a 'women's issue' when it can be casued by, and affects both partners equally. It is true that financially stable couples may pursue treatment after the initial NHS offer but this must remain in order to give equality of access to treatment
I feel women are discriminated against as they are limited to one cycle. A male partner though can move onto another relationship and have more cycles. This kind of discrimination should not exist in this day and age
I simply hope it's a darned sight better than when we were trying to have a baby - it was a level of care that can only be described as shocking. I hope no one else ever has to experience it in the same way we did
I would like Care Fertility Northampton to become a provider for NHS fertility services for patients living in the Bedford and Luton area , we already are a provider for patients living in Milton Keynes.
If these services are cut we cannot afford to pay ourselves. I am a teacher who gives a lot to society and deserve a good chance in fertility.
Include those needing a surrogate - this isn't a choice, this is a medical condition causing surrogacy to be the route we need
Instead of targeting people who want babies, encourage people to get healthy and fitter to stop them getting ill in the first place and this will save money long term
It is a shame there is no option 3, where luton goes down to 2, Bedfordshire and MK go up to 2 and the service is extended to same sex female couples and any person with a uterus.

It is horrifying and heartbreaking that in reading berkshire, as I had a child at 21 I can not access any help to have ivf after having two ectopic pregnancies that took a tube each time. My partner does not have children and is no the father to my child. It is barbaric and sadly we may never be able to afford having a child together
IVF should not be available on the NHS to any individual or couple who have not attempted to conceive naturally over a period of at least a year. There is a vast difference between those who cannot conceive despite trying and those choosing not to conceive through natural methods due to sexual or other preference. Whilst all those who seek to be loving parents should have this opportunity, alternative options such as adoption are more appropriate where conception is not possible due to choice.
Make treatment for a second child available if IVF is the ONLY option, eg tubal factor where there is 0% chance of conceiving naturally
Neither option. In view of the cost to the economy of Covid19, I would prefer the minimum national option.
NICE guidance is based on what is clinically and cost effective. There is no reason not to follow this locally. There is no explanations of your cost projections or of how these were reached which is extremely poor. You have not consulted before offering these options to the public which is also very poor. Are you going to be offering full cycles? Why did you decide not to give people the option to suggest two cycles? On what basis did you decide to give these two options only? Infertility is defined by the WHO as a disease and NICE has judged IVF to be a cost effective treatment for this, based on the provision of three full cycles. Unless you have evidence to the contrary, you should be following NICE guidance.
No increase in fertility services, reductions only. Promote adoption.
No IVF should be funded at all, for anyone, unless infertility was the outcome of an illness (eg cancer treatment) or injury. Why is this not an option being considered?
None of the above. Support an increase in available cycles to those that are eligible to three as in Luton.
not a priority
Previous sterilisation- to consider special circumstances where it may have been carried out (eg in previous relationships where partners were in abusive relationships)
There is clear discrimination against women in the policies. "Women" are entitled to 1 fresh cycle, but men can have as many as they please. It doesn't allow for relationship breakdowns caused by the stress of this problem and so doesn't allow a new couple treatment even if the male hasn't had treatment.
Those who need a donor should be referred to clinics WITH DONATION PROGRAMS more easily
To be entitled to more fertility treatments
To reduce will have a HUGE impact on mental health and reduce hope in an already depressing world
Uk resident for at least 3 years prior to treatment
We actually have a declining population and an ageing one. It’s unusual for IVF to be successful first time so women need a decent chance.
We conveniently got delayed in the system whilst trying to qualify for IVF on the NHS in that time the number of rounds changed from 3 to 1 without out knowledge.
You should not be reducing this! Sometimes it takes more than one cycle! Not everyone is lucky enough to conceive on the first try!!!!
Your woke shit will be your downfall. People are getting sick of it. "People with uterus..."

Q9 Are there any other comments you would like to make regarding gluten-free food on prescription?

Q9: Cost of gluten-free food
but families with a child on this diet would find the bread especially very expensive, or indeed anyone on a low income.
Gluten free food is very costly - even options when eating out [few as they may be] are generally more expensive too. Vegetarians and vegans are catered for - and theirs is a "choice" - but requiring gluten free food is not "optional" for coeliacs!
As a mother to a child with multiple food allergies (not gluten) I have a huge amount of concern for those families/individuals who would be unable to fund this themselves. Many will be struggling with higher bills, higher cost of food etc, and so would be forced to go without a basic food. This will make it harder for teens to take lunch to school, or adults to eat healthily at work. Many lower paid jobs don't have anywhere to store or prepare foods, so bread is essential, but not when it costs so much for specialist bread.
As a person who has to eat gluten free food for over 25 years it is just getting so expensive A loaf for someone with out needing Gluten free £1 Gluten free loaf £2.05 at least and the loaf is much smaller. I I just ate normal bread I would be sick and cost the NHS more money
Although availability of gf food has increased in supermarkets it is on average 3 times more expensive and not always available in smaller shops. There is no choice to have 'normal' products it is essential to have 100% gf diet every day for life. The most vulnerable will struggle without the provision of staples of gf bread and flour being available via prescription which could lead to not adhering to the diet, becoming unwell and therefore costing BLMK more in the long run.
G f food is extremely expensive and Mk not providing this will definitely stop many children and young people accessing food particularly those families on lower incomes
Having coeliac disease and being gluten free is not a choice like vegetarian or vegan. It is an incurable disease and the food is the "medicine" if it cost the same as normal food it would be different but when it is 3 times the price it is very hard for patients who have no choice once diagnosed with this incurable disease
I have ticked option two, not because I think everyone should be prescribed gluten free bread and flour, but because I am appalled at the thought that you will take away GF bread and Flour to those that are on Universal Credit. People shouldn't be at risk of nutritional harm before getting gluten free bread and flour on prescription.
I have two friends locally who have symptoms of coeliac disease and have specifically refused to be tested for it because they cannot afford to buy gluten-free foods. I believe the current policy in MK is seriously harming people's health and costing the NHS significant amounts in continuing to prescribe other medications to treat the symptoms of people who would be far healthier if they could access gluten-free food on prescription. It seems the CCG is simply out of touch with the realities of food costs for many of the population. As food becomes ever more expensive and benefits continue to be reduced, more coeliacs will either stop eating gluten-free food or not start doing so because of this regressive policy. Asking a GP for special consideration if unable to afford gluten-free food simply does not work. I know one coeliac locally who has asked and been refused, so now eats gluten-containing food because she cannot afford gluten-free.
I think it is difficult to clarify how the safety net for, 'patients at risk of nutritional harm' would work in practice, and would want this to be ensured to make this change. However, GF products are now widely available, and often not much more expensive than gluten products. It seems strange for personal dietary, rather than personal affluence to be the guiding principle.
I'm a single parent on low income. I have no choice in having to eat Gluten free food. It is far more expensive than "normal" food and I am struggling to afford it. Coeliac disease is a life long medical condition so should be treated as such and the food or "treatment" be made available on prescription.
If it would cost the NHS a lot of money to provide prescriptions for gluten free food, think of how much it costs the public. On average a small loaf of gluten free bread costs me 2 and a half to 3 times as much as a normal loaf of bread, which is almost twice the size. I'm paying a lot of money for my health condition, which isn't my choice.

It is not a choice it is a necessity. The easiest flours for coeliacs to use (by just substitution in normal recipes)are the codex ones containing wheat but no gluten. Eg glutafin white mix select. They cost approx £10- £15 for only 500g. The lack of varied readily available gluten free foods makes home cooking essential. The pandemic has made this worse. Coeliacs already have to pay greatly inflated prices for their food eg bread or pasta. Prescription of flour is not a luxury item, you can't eat a bag of flour! It requires time effort and the purchase of more ingredients to be usable. Prescription availability encourages patients to stick to their difficult diet which in the long term will reduce long term complications which would cost far more nhs money to fix
More gluten free food on prescription. It's very expensive having a disease which I cannot help having.
Most of this good is now available to purchase in supermarkets and unlike a few years ago is an equivalent price to non gluten free so it would save ccg money to remove this from the prescribing list
much more readily available nowadays, and at more reasonable prices
My husband requires GF food and we are happy to pay for it as we can afford it. I think this should absolutely be provided if people can't fund it themselves
Naturally occurring gluten free food is widely available - meat, fish, vegetables, potatoes, fruit, nuts. By offering prescribed gf food it makes people forget that there is so much fresh food available - thus having an negative impact on the quality of diet. Education is key. And maybe pressure on the government to supplement gf bread uk wide to bring it in line with the price of normal bread
Or bring the price of gluten free products down compared to the normal food
People with gluten intolerance are at risk of food poverty because of the higher cost of buying gluten-free foods
The broad range now available at competitive prices supports option one
I am 71. I have had gluten free prescriptions since 1991. Until I reached retirement age, I had to pay the going rate of prescription tax on those - usually with an annual pre-payment certificate. Anyone who believes that gluten free bread is easily available is sef delusional and has not visited a supermarket recently. It is 3-6 times more expensive than ordinary bread and only one fifth of the equivalent shelf space is given to it.
This is an incredibly expensive option, I understand that, but there are individuals who have to go without other essentials if this is not funded.
This must ONLY be implemented if those in lower socio-economic households can easily access the gluten-free foods they require. It cannot be used simply as a (relatively small) cost-saving measure, which results in many people missing out. This is particularly important in the Luton area where people are used to the service, and where recipients are more likely to be from a BAME background, with lower levels of English langauge and integration. Any change should be communicated with a campaign in multiple languages to ensure that people are aware and are able to seek the support that they need.
We should campaign for manufacturers and retailers to reduce the price of these products
Why is it not available for children and in Bedfordshire. Gf food is so expensive so either lower prices or provide access to prescriptions for under 18s
Would be more useful if retailers / suppliers were made to offer the products at the same price as regular items. They are normally way more expensive and for less.
Q9: Dietary education
but the money could be saved by teaching people to cook using gf options
Lots of receipes to make own products easyily accessed.
Surely the NHS is there to diagnose the problem - and tell the person concerned - eat rice, potatoes and meat and veg.
I believe these days gluten free options are more widely available and while people with specific dietary needs should have continued support, the CCG does not need the extra administrative cost of issuing prescriptions. Advice together with universal credit/social security considerations should suffice.
I think if an education programme could be invested in and developed and promoted to people that are cealiac or gluten intolerant this would be more beneficial than simply prescribing the gluten-free food. Whilst not quite the same health condition, I was lucky enough to be 'prescribed' access to the 'National Diabetes Prevention Programme', this about 10 months of education, support from health coaches, the advice and re-education I learned about foods has changed how I eat, what I eat, and what ingredients to look out for, keeping a food diary.

Conincidentally, many low-carb whole foods, are also gluten free! Rather than prescribing gluten free bread, encourage making your own gluten free alternatives, healthier, and you know exactly what is in that recipe, better for your health.
Naturally occurring gluten free food is widely available - meat, fish, vegetables, potatoes, fruit, nuts. By offering prescribed gf food it makes people forget that there is so much fresh food available - thus having an negative impact on the quality of diet. Education is key. And maybe pressure on the government to supplement gf bread uk wide to bring it in line with the price of normal bread
This must ONLY be implemented if those in lower socio-economic households can easily access the gluten-free foods they require. It cannot be used simply as a (relatively small) cost-saving measure, which results in many people missing out. This is particularly important in the Luton area where people are used to the service, and where recipients are more likely to be from a BAME background, with lower levels of English langauge and integration. Any change should be communicated with a campaign in multiple languages to ensure that people are aware and are able to seek the support that they need.
Q9: Gluten-free food in shops and supermarkets
There is a wide choice available of GF food in the shops,
As gluten free options are widely available in supermarkets these days, prescriptions should be limited to those with financial difficulties, given this food is generally more expensive.
Although availability of gf food has increased in supermarkets it is on average 3 times more expensive and not always available in smaller shops
For the most part, part gluten free products and alternatives are widely available in most supermarkets at an affordable price without having to resort to using NHS resources.
GF products are widely available in all major supermarkets. They are not difficult to come by and can be purchased at reasonable prices. In my opinion, a prescription is not necessary.
Gluten free food is not difficult to access in major supermarkets.
Gluten free food is now readily available in most if not all shops & supermarkets
Gluten free food is now readily available in supermarkets
Gluten free food now available in supermarkets with a wide range available so why is the NHS paying for it
Gluten free foods are now freely available in a large range of retailers and the increased availability coupled with the fact that the prices are reducing means this is no longer necessary for the majority of patients. The exceptions should be those on a low income which could be more adversely affected
Gluten free item are so readily available now that i do not feel prescriptions should be given
Gluten free products are cheap enough for people to purchase in the shops.
Gluten free products are readily available in shops and on-line.
Gluten free products widely available- no need to have on prescription
Gluten-free food and ingredients are freely available in supermarkets. Pricing is higher than that of conventional foods, but not prohibitively so. The NHS should not be involved in supply, only in advising.
Having an enforced gluten (wheat specifically) diet for ten years I can say that food is fairly easily available (albeit at a premium) so I agree that the at risk should be allowed access via prescription. It's still an inconvenience at restaurants and shops having to ask for allergen information, but that doesn't change if available on prescription. I'm with CCG on this one - it is no longer needed. I bought five bags of GF flour from Amazon last week with one click, cheaper than cost of a prescription!
I believe that gluten-free bread and flour is now more accessible, and if those at risk of nutritional harm are still being supported, I feel confident that there are ways to sustain the needs of those who still need these products.
I don’t feel it is a necessity as there are many naturally gluten free options available as well as supermarket products. If it is an extreme case and a person is very sensitive to gluten then it should be considered to prevent further difficulties for them but should not be automatically available to all diagnosed with coeliac disease.
Buying it from the supermarket is very very expensive. Coeliacs shouldn't be hugely out of pocket for their illness and people on universal credit struggle enough as it is without having to pay extortionate prices. As and example Tesco's cheapest standard bread is 36p for an 800g loaf, that is about 4p/100g their cheapest gluten free loaf is

£2.50 for 535g, which is about 47p/100g, that is nearly 12 times the price. Gluten free staples are very very expensive. People on universal credit should get bread and flour on prescription.
I think it is difficult to clarify how the safety net for, 'patients at risk of nutritional harm' would work in practice, and would want this to be ensured to make this change. However, GF products are now widely available, and often not much more expensive than gluten products. It seems strange for personal dietary, rather than personal affluence to be the guiding principle.
In the majority of supermarkets there is a wide range of gluten-free products available at reasonable prices. To have it on prescription now is a waste of money that could be used on more important things.
Most of this good is now available to purchase in supermarkets and unlike a few years ago is an equivalent price to non gluten free so it would save ccg money to remove this from the prescribing list
much more readily available nowadays, and at more reasonable prices
Supermarkets nowadays stock a reasonable selection of gluten-free foods. It seems unnecessary to offer them on prescription.
I am 71. I have had gluten free prescriptions since 1991. Until I reached retirement age, I had to pay the going rate of prescription tax on those - usually with an annual pre-payment certificate. Anyone who believes that gluten free bread is easily available is sef delusional and has not visited a supermarket recently. It is 3-6 times more expensive than ordinary bread and only one fifth of the equivalent shelf space is given to it.
There are ample options available in supermarkets today compared to previous years. There are no similar policies in place for other patients with allergies such as dairy.
There is so much gluten free food available in all major supermarkets now at reasonable prices. There is no need to prescribe it and it would save a lot of money.
Q9: GP annual review
Accessing gluten free prescriptions means that the GP has to do an annual review. This has not happened since gluten free prescribing ended in Bedford Borough. Significant changes in the health of coeliacs may be missed by this decline in annual reviews
Q9: Inequality across Local Authorities
If Luton can get gluten free on prescription then Bedfordshire should also be allowed too as bread is so expensive when on a limited income.
It is unfair that some areas receive GF food on precription whilst in Milton Keynes we don't
Make it accessible in central Bedfordshire.
My Dad is coeliac and is unable to get prescription products from his GP surgery in Ampthill. It's not fair that it is available 10 miles down the road
There should be fairness across the area and absolutely there should be support for those who are gf through not dietary choice- it’s a medical condition
Why is it not available for children and in Bedfordshire. Gf food is so expensive so either lower prices or provide access to prescriptions for under 18s
Why is Luton so over subscribed with funding, all this reducing Luton’s budget nonsense - we are expanding!!! Need I stress again.
Q9: Limits on prescriptions (either by people eligible or by type of food)
16 years ago I found it very helpful to get gluten free foods on prescription as it was so much more expensive then and it was a huge challenge to change my diet completely. I suggest that all newly diagnosed patients should get gluten free prescriptions for the the first 3 or 6 months, to enable them to adapt to their new diet.
prescriptions should be limited to those with financial difficulties, given this food is generally more expensive.
Clear limits should be set out eg 1 loaf of bread a week
Gluten free brad etc should not be on prescription. These are very mainstream abd widely available with different price points and now affordable and in line with non gluten breads. Unnecessary spending for the NHS
Gluten free foods are now freely available in a large range of retailers and the increased availability coupled with the fact that the prices are reducing means this is no longer necessary for the majority of patients. The exceptions should be those on a low income which could be more adversely affected
Gluten free is much more affordable now so only those who can't afford it should get assistance

Pricing is higher than that of conventional foods, but not prohibitively so. The NHS should not be involved in supply, only in advising.
I am not a diagnosed coeliac, but alongside my two sons (and father before me), any gluten containing substance provides us with days and sometimes weeks of misery. We therefore avoid all gluten; including wheat or oats alleged to be gluten free and which also cause problems. However, as with Coeliac disease our problems are solved by the avoidance of the problematic substances. It requires no medication as far as I am aware. As all people must eat - I do not see why the general public or taxpayer should provide anyone with 'free food'. Surely the NHS is there to diagnose the problem - and tell the person concerned - eat rice, potatoes and meat and veg. The cost of a weekly loaf of bread is not going to impoverish anyone. If someone wants cake for instance - that is a luxury not a necessity. Are you The National Health Service or the National Food Service? It should never have gone on the list. With the exception of the poor and poor children this is just one of those things we should be responsible for and not expect the State to pay. Sainsburys and their ilk have an enourmous section of gluten free foods - it is not difficult to find.
Buying it from the supermarket is very very expensive. Coeliacs shouldn't be hugely out of pocket for their illness and people on universal credit struggle enough as it is without having to pay extortionate prices. As and example Tesco's cheapest standard bread is 36p for an 800g loaf, that is about 4p/100g their cheapest gluten free loaf is £2.50 for 535g, which is about 47p/100g, that is nearly 12 times the price. Gluten free staples are very very expensive. People on universal credit should get bread and flour on prescription.
I think that in general there should be more options on prescription
I think this needs to be particularly available and easily accessible for under 16's.
I would prefer you provide a fertility offering in line with NICE rather than gluten free bread. Although I assume only people who get free prescriptions because they can't afford to buy gluten free bread benefit from this? I think this could be means restricted
It's import to ensure people who have a genuine health need and maybe unable to afford these items still can have them prescribed
More gf food available on prescription
More gluten free food on prescription. It's very expensive having a disease which I cannot help having.
More options for GF food should be available on prescription.
My husband requires GF food and we are happy to pay for it as we can afford it. I think this should absolutely be provided if people can't fund it themselves
Other gluten free products should be available for children (under 18), and for any patients at risk of nutritional.
Please note i am not advocating free GF foods generally, just the staple foods to help with the not inconsiderable cost of food because of something i was born with.
Should only be available to patients entitled to free prescription for economic reasons - ie exclude patients who have free prescription for other reasons, such as age or other conditions.
Why is it not available for children and in Bedfordshire. Gf food is so expensive so either lower prices or provide access to prescriptions for under 18s
Would be helpful if it was at least offered to under 18s and funding provided for schools to provide a fair gluten free lunch option. Could be beneficial to families struggling with expensive gluten free options for children.
Q9: Mention of coeliac disease or other medical condition
Actually coeliac disease can be life threatening it is very understated in the consultation documents. Access to gluten free basic food is as vital as medicines.
As a coeliac I have an interest in this. I buy my own gluten free products
As a coeliac, having to go gluten free is not a "lifestyle choice" - it is medically essential to remain healthy & avoid future health problems requiring intervention & treatment from the NHS.
coeliac disease is an autoimmune disease for which there is no cure and no treatment apart from a gluten free diet
Eating gluten free food is essential for someone with CD and access to prescription food shouldn't be a postcode lottery
Coeliac disease needs to be taken seriously - children are often excluded from parties, school activities etc as is - they need a staple diet.

Having coeliac disease and being gluten free is not a choice like vegetarian or vegan. It is an incurable disease and the food is the "medicine" if it cost the same as normal food it would be different but when it is 3 times the price it is very hard for patients who have no choice once diagnosed with this incurable disease
I am not a diagnosed coeliac, but alongside my two sons (and father before me), any gluten containing substance provides us with days and sometimes weeks of misery. We therefore avoid all gluten; including wheat or oats alleged to be gluten free and which also cause problems. However, as with Coeliac disease our problems are solved by the avoidance of the problematic substances. It requires no medication as far as I am aware. As all people must eat - I do not see why the general public or taxpayer should provide anyone with 'free food'. Surely the NHS is there to diagnose the problem - and tell the person concerned - eat rice, potatoes and meat and veg. The cost of a weekly loaf of bread is not going to impoverish anyone. If someone wants cake for instance - that is a luxury not a necessity. Are you The National Health Service or the National Food Service? It should never have gone on the list. With the exception of the poor and poor children this is just one of those things we should be responsible for and not expect the State to pay. Sainsburys and their ilk have an enourmous section of gluten free foods - it is not difficult to find.
I have coeliac and I have no access to any free food on prescription. This should be made available to everyone.
I think this service should be extended to those with gluten intolerance borderline gastroperesis & other conditions with this intolerance.
I'm a single parent on low income. I have no choice in having to eat Gluten free food. It is far more expensive than "normal" food and I am struggling to afford it. Coeliac disease is a life long medical condition so should be treated as such and the food or "treatment" be made available on prescription.
It is not a choice it is a necessity. The easiest flours for coeliacs to use (by just substitution in normal recipes)are the codex ones containing wheat but no gluten. Eg glutafin white mix select. They cost approx £10- £15 for only 500g. The lack of varied readily available gluten free foods makes home cooking essential. The pandemic has made this worse. Coeliacs already have to pay greatly inflated prices for their food eg bread or pasta. Prescription of flour is not a luxury item, you can't eat a bag of flour! It requires time effort and the purchase of more ingredients to be usable. Prescription availability encourages patients to stick to their difficult diet which in the long term will reduce long term complications which would cost far more nhs money to fix
Q9: Prescribed food for other conditions
I don't find fair that only people suffering from gluten have access of products paid by the tax payers. There is other severe allergies sufferers with no access to free prescriptions.
Prescriptions should be available for those with gluten intolerance too. Going gluten free is not a choice but a necessary way of life to prevent very uncomfortable, debilitating and serious illness that may cause long term complications. Included should be those with autoimmune issues where gluten can cause inflammation and flare ups of such conditions.
To extend this to other alimentary restrictions like lactose and other allergies
Whilst I understand that those with Coeliac are 'at risk of nutritional harm' - those with IBS with relatively severe symptoms are likely to be undergoing the Low-FODMAP diet. Those undergoing the elimination phase of the diet for IBS should also be prescribed these foods as it is the most expensive bit of the elimination diet and could prevent someone on a lower income from being able to properly do the elimination diet.
Q9: Food should not be provided by healthcare
Gluten free products widely available- no need to have on prescription
Gluten-free food and ingredients are freely available in supermarkets. Pricing is higher than that of conventional foods, but not prohibitively so. The NHS should not be involved in supply, only in advising.
Gluten-free food on prescription is a complete waste of public money. It is NOT expensive to eat a balanced, gluten-free diet. People should fund that themselves.
Surely the NHS is there to diagnose the problem - and tell the person concerned - eat rice, potatoes and meat and veg.
I don't think it is the role of healthcare providers to provide food.
I find it odd to prescribe gluten free food

In the majority of supermarkets there is a wide range of gluten-free products available at reasonable prices. To have it on prescription now is a waste of money that could be used on more important things.
People are very able to buy their own food for goodness sake. We can buy cigarettes / toys etc. Why not food? In other parts of Europe - this is not free!!
Poor use of funding to prescribe - gluten free food is affordable and accessible in the community now.
Prescribing was ok when these foods were scarce and expensive. They are now readily available everywhere at prices far less than prescriptions. There is no need to prescribe g/f anything. Not good use of public funds.
Supermarkets nowadays stock a reasonable selection of gluten-free foods. It seems unnecessary to offer them on prescription.
There is so much gluten free food available in all major supermarkets now at reasonable prices. There is no need to prescribe it and it would save a lot of money.
Why should they het free food on the NHS?
Q9: Subsidy
I believe gluten free patients should have a card that entitles them to pay the same price of normal bread for gluten free products
I believe that gluten-free bread and flour is now more accessible, and if those at risk of nutritional harm are still being supported, I feel confident that there are ways to sustain the needs of those who still need these products.
I have ticked option two, not because I think everyone should be prescribed gluten free bread and flour, but because I am appalled at the thought that you will take away GF bread and Flour to those that are on Universal Credit. People shouldn't be at risk of nutritional harm before getting gluten free bread and flour on prescription.
Q9: Other
(NB sometimes these comments are duplicated elsewhere, if part of the comment falls into another category; they have been placed here because another part of the comment cannot be placed under a main category)
Funds could be better spent elsewhere.
Gluten-free food on prescription is a complete waste of public money. It is NOT expensive to eat a balanced, gluten-free diet. People should fund that themselves.
Go with extending best practice over cost saving, always
I don't think now is the right time to start cutting things given the rise in food insecurity.
I feel that products should state limited shelf life and patients with gluten free goods should be made aware of when products are delivered.
I think it is difficult to clarify how the safety net for, 'patients at risk of nutritional harm' would work in practice, and would want this to be ensured to make this change. However, GF products are now widely available, and often not much more expensive than gluten products. It seems strange for personal dietary, rather than personal affluence to be the guiding principle.
in general there should be more options on prescription
I would prefer you provide a fertility offering in line with NICE rather than gluten free bread. Although I assume only people who get free prescriptions because they can't afford to buy gluten free bread benefit from this? I think this could be means restricted
just use food banks if necessary
Many people have intolerances and still have to purchase items - my daughter has significant eczema and her local GP Oliver Street has refused to prescribe a cream which is available on prescription because she should buy it herself - she uses so much she spends £50 a month on cream - bread and flour is cheaper !
Offer more gluten free tests to general population
People should have access to the food they need to remain well where ever they live
Please bring back flour and bread
should not be a priority
So freely available now that very few will need it on prescription
that people who do not live in UK and staying in this country for a short while should not be able to have access to free gluten products
The flours/bread available on prescription are more nutritious and healthy than those available commercially.

The increased amount you would pay on option 2 must be balanced against what problems have arisen from withdrawing gluten free prescribing in Bedford and MK CCGs. You carefully avoid stating how many cases of repeated villius atrophy there were before you stopped gluten free prescriptions and how many there were afterwards. It is one thing to stop gluten free prescriptions for new cases where diagnosis is confirmed through flattened villi on upper GI endoscopy from a future date, eg 01 Jan 2023, and another to take the provision away from existing claimants.
Once you place gluten free products into the commercial sector alone you will have the gluten free equivalent of horsemeat in burgers and an epidemic of flattened villi with symptoms of Gluten Intolerant Enteropathy overwhelming your GI department. The number of pensioners who have died of COVID 19 in the 146,000 deaths probably accounts for a Government saving of 500 million pounds in pension payments at a minimum so now refusing to treat our Gluten Intolerant Enteropathy is an extraordinary act of spite and malice presumably advocated by obese smokers of working age who steal their gastric band and lung cancer operations out of my pension and blame pensioners for everything wrong with the health service. I note the vast fortune you propose to spend on IVF for women with a BMI of 30 which is clinically obese - BMI 40 is morbidly obese - thus normalising obesity and financing the diabetes, heart disease and knee and hip joints by leaving me to die of flattened villi. You can also afford to treat anyone with type 2 diabetes self inflicted by a BMI of 30 with free insulin whereas you ask me to pay for what is required to mitigate an autoimmune IgA T Lymphocyte reaction to gliadin over which I have no control. You have projected an increased expense of GBP 174,000 from a cost of £528 each per year from the 100 Luton CCG patients without setting out why NHS procurement, once famously described as a smoking ruin, is so poor. What is the cost of a colonoscopy and an upper GI endoscopy that are likely to be needed if I don't eat gluten free bread? Option 1 is a false economy and act of spite at at time of pension cuts, fuel and energy costs increased by 30%, tax rises and a council tax burden that has risen in the last 5 years from 10.9 percent of my state pension to 12.3 percent. Option 2 is most cost effective since it is a pale shadow of the cost of giving IVF to obese women.
There are ample options available in supermarkets today compared to previous years. There are no similar policies in place for other patients with allergies such as dairy.
There should be other options available that are a staple food i.e. pasta, cereal etc. People don't just live of bread!
This is an incredibly expensive option, I understand that, but there are individuals who have to go without other essentials if this is not funded.
This must ONLY be implemented if those in lower socio-economic households can easily access the gluten-free foods they require. It cannot be used simply as a (relatively small) cost-saving measure, which results in many people missing out. This is particularly important in the Luton area where people are used to the service, and where recipients are more likely to be from a BAME background, with lower levels of English langauge and integration. Any change should be communicated with a campaign in multiple languages to ensure that people are aware and are able to seek the support that they need.
Would be nice if you could find out a way to test without eating it! I did an elimination diet to see (back in 2002). They nhs thought I was nuts when I explained it to my doctor at the time.

Q12 Are there any other comments you would like to make regarding the Pharmacy First Minor Ailment Scheme?

Q12: Didn't know about it/needs wider promoting
I didn't even know it was still running! I often speak with patients who are unable to access medication through the old minor ailments scheme, and are signposted back to the GP by the pharmacist. I often prescribe OTC medication because the patient says they cannot afford to buy it.
IF it is the case (as your documentation suggests) that the MKPFMA scheme is effectively the same as the national CPCS scheme then this is acceptable. Public campaigns highlighting any such changes should be run to ensure that the public are aware that the service is being replaced with a similar service. If this will result in greater pressure on GPs and A&E services for minor problems then such a removal should be reconsidered.
It is sad that the MK scheme has not been used extensively. It was a good idea.
It needs wider promoting I had to look up what the scheme meant
It's not something I was previously aware of (I have lived in Milton Keynes and also well connected within this area). That said, without looking at data and support needs, I feel that I am offering a biased opinion based on my own needs.
Not widely advertised. The general public do not know about the scheme. I had to look it up on line.
Q12: Generally negative comments/not worth it/no value
I can't really see the value in it.
I do not accept that either option is necessary or proportionate.
Many medications are cheap over the counter and can be bought.Do not need prescribing
Pharmacists are not doctors. Stop pushing people to self treatment and provide comprehensive and proactive care and you'll see the number of people needing NHS for critical things to decrease.
The service is available to obtain low value medicines and is not a good use of NHS resources compared to other treatments the NHS has to fund.
Q12: Generally positive comments
Being able to access medical treatment at your local pharmacy is going to be vital, particularly as getting a GP appointment currently is a lengthy process, 4 weeks wait and longer for a GP appointment in MK, local pharmacies are a real lifeline.
Community Pharmacy Consultation Scheme more cost effective solution without loss of service.
easier to access a pharmacy than a GP and can avoid going to the urgent treatment centre at MKGH
Good scheme
I think its a good idea
I think that any service that can be provided to help those with health issues should be provided. We already pay for a health service through all taxes. I don't think we should be paying more for receiving less.
Pharmacists are highly qualified clinical leaders that the public should use after 111 for minor s as ailments
Seems like a cost-effective way of promoting health.
This is a valuable safety net for people who are on low income and are not able to purchase OTC medicines. The CPCS does not help this group as it still requires payment for items. Patients will go to A&E or walk In Centre to obtain medicines free of charge.
To me it sounds like MK has something extra that can help people access help and advice quicker. Agree with the other two on this document but think this sounds like an addition to the Luton and Bedford. Also sounds like a give when taking the other two :)
Q12: In favour of expansion
as almost impossible to see a GP the service should be expanded
I think this is a great idea and should be extended to include more ailments. Sometimes minor issues could be treated with prescription medicines that a pharmacist could easily and appropriately prescribe, particularly if a patient has a known medical issue. This would be much faster and take some of the pressure off local GP services.

It is sad that the MK scheme has not been used extensively. It was a good idea.
Signposting to pharmacy first is already in NHS messaging. Expanding this to a pharmacy first minor ailment scheme would be really helpful.
Q12: Takes pressure off A&E/hospitals
A&E and GP services are overstretched and an increased role for pharmacies would be of considerable benefit.
Anything to take pressure off GPS and A&E
If this will result in greater pressure on GPs and A&E services for minor problems then such a removal should be reconsidered.
In Bedford the population is rapidly expanding and the GP services are unable to keep up. In my own area the GP is complained about and had changed hands several times. Taking the pressure off of the GP and giving another option would give more people a chance of getting appropriate medical help without then flooding A&E in desperation
It seems sensible to retain this scheme in some form. It reduces pressure on A&E and GPs and potentially provides OTC medicines to those who would otherwise not have access to them. It is also for Minor Ailments which will get worse if not treated - so probably money well invested.
It would probably relieve the over-stretched A&E departments.
Minor Ailments is a valuable pharmacy service that links into the CPCS service and provides patients with the treatment they need, reducing the burden on GP surgeries and emergency services.
This is a great service and reduces pressure on GP and hospitals
We need to ensure adequate provision of minor treatment availability as we need to discourage attendance at A and E and busy GP services where treatment is readily available elsewhere.
Q12: Takes pressure off GPs
A&E and GP services are overstretched and an increased role for pharmacies would be of considerable benefit.
anything to help take pressure off GP services must be a good idea
Anything to take pressure off GPS and A&E
as almost impossible to see a GP the service should be expanded
Being able to access medical treatment at your local pharmacy is going to be vital, particularly as getting a GP appointment currently is a lengthy process, 4 weeks wait and longer for a GP appointment in MK, local pharmacies are a real lifeline.
easier to access a pharmacy than a GP and can avoid going to the urgent treatment centre at MKGH
I think this is a great idea and should be extended to include more ailments. Sometimes minor issues could be treated with prescription medicines that a pharmacist could easily and appropriately prescribe, particularly if a patient has a known medical issue. This would be much faster and take some of the pressure off local GP services.
If this will result in greater pressure on GPs and A&E services for minor problems then such a removal should be reconsidered.
In Bedford the population is rapidly expanding and the GP services are unable to keep up. In my own area the GP is complained about and had changed hands several times. Taking the pressure off of the GP and giving another option would give more people a chance of getting appropriate medical help without then flooding A&E in desperation
It seems sensible to retain this scheme in some form. It reduces pressure on A&E and GPs and potentially provides OTC medicines to those who would otherwise not have access to them. It is also for Minor Ailments which will get worse if not treated - so probably money well invested.
it will help GPs to manage clients
It's really hard to get a doctors appointment so this scheme helps you get medical advice for minor issues
Need to use pharmacies more to relief gp
Poor access to GPs needs the support of pharmacists.
This is a great service and reduces pressure on GP and hospitals
This scheme takes pressure off the GP surgeries when they are already struggling as it is.
We need to ensure adequate provision of minor treatment availability as we need to discourage attendance at A and E and busy GP services where treatment is readily available elsewhere.

Q9: Other
(NB sometimes these comments are duplicated elsewhere, if part of the comment falls into another category; they have been placed here because another part of the comment cannot be placed under a main category)
I didn't even know it was still running! I often speak with patients who are unable to access medication through the old minor ailments scheme, and are signposted back to the GP by the pharmacist. I often prescribe OTC medication because the patient says they cannot afford to buy it.
I feel the system is abused in MK; the details of how to get free medicine is shared on social media and it affects those that do actually need it.
Cutting access to health services is likely to increase budgets elsewhere. Prescribing only generic medicines would probably save money, e.g. the difference between supermarket brand analgesic and branded ones.
It should always remain a choice, not a mandatory pathway.
It’s important that residents are treated the same across BLMK
Items like paracetomol and ibroprofen cost less than 50p at some supermarkets and many individuals would have to pay more than that in bus fares to get them at this price and it is unreasonable to expect them to pat a £9 prescription charge. If this cannot be rolled out can the cheaper items not be made available in the local pharmacies as a matter of good practice?
Pharmacies already offer advice on minor ailments and most products are already in homes, such as paracetamol tablets and if not are very cheap to buy.
Reducing the need to access secondary care is paramount. We know community services do this.
This need would be better dealt with by encouraging GPs (or nurses in GP practices) to prescribe for minor ailments when required, on both medical and cost grounds.
We are always getting asked to provide medicines as we are located in underpriviledged areas of luton.
Would like to ensure that savings made are retained in community pharmacy

Q13 Please provide us with any other comments regarding this public consultation

Q13: Additional comments on fertility services
Everyone should be given a chance to become a parent.
Everyone should be given an opportunity to have a baby. NICE guidance suggests on average it takes 3 rounds so everyone should be given this opportunity.
Fertility services across the uk should be aligned and not be a post code lottery. I pay my taxes just like others and should be able to access the services I require from the nhs.
Fertility treatment for single women and same sec couples is a waste of funds. NHS should only be treating if there is medical need. Single women is a choice and same sex is not a medical reason. Many other medical needs in the NHS these funds can be spent on.
Health services should be appropriately funded for all across BLMK to promote the health and fertility of everyone.
how dare you want to restrict fertility
I am currently accessing fertility services and feel more rounds of IVF and swifter diagnoses should be available. I further feel all tests relating to fertility issues should be conducted by the same department eg to include semen analysis which currently has to done through your GP instead of the consultant at the hospital. This causes delays especially if your GP doesn't want to refer for those services feeling they are not urgent (as happened to us).
I believe same sex couples should have access to the fertility treatment that heterosexual couples do
I have seen up close how fertility issues impact a couple, their mental health and their wellbeing. IVF should be available to all, and as many cycles as possible should be offered. It would be disappointing if you reduce this service further rather than extend it further.
I will write to my member if parliament and state that you are pushing ideas such as "people with uterus" at the expense of women's rights.
It seems unfair for Luton to reduce their number of IVF rounds considering the NICE guidelines and data suggest that 3 rounds of IVF is optimal and would also have an impact on the number of people accessing mental health services due to being unable to have their dream of a child when they have no other option
One cycle of free IVF in Milton Keynes is too limited and not fair on people trying to conceive. Increasing the number of cycles increases the chances of conception and brings hope to families.
Please consider the patient implications of cutting fertility treatment allocation by two thirds. As a patient in the system when treatment allocation was cut by two thirds in Central Bedfordshire a few years ago, I can tell you the emotional and physical health implications are significant. Such decisions also negatively impact all other aspects of life. I also ask you to consider (what was then) Bedfordshire Clinical Commissioning Group's evidence based report that clearly showed the cost of cutting fertility services will far exceed the savings made, and therefore decided not to implement the proposal. The report was written by Donna Derby. If you are going to make a change to your treatment allocation, please bring the allocation up to three cycles for all – which is in line with NICE guidelines.
Same sex couple have as much right - and need - to become parents as mixed sex couples. Simple as that. Do not discriminate against them.
Q13: Additional comments on gluten-free prescribing
I hope you decide to reinstate gluten free prescriptions in MK. I am glad to have had the opportunity to comment. If not a member of coeliac uk however, I would never have known about this opportunity. It should be more widely publicised.
Q13: General negative comments on the consultation
I could not find a specific email address to send my comments in full. I do not believe this is a consultation. Representations are most likely to be ignored as you have already made up your minds.

Q13: General positive comments on the consultation
All of this is great but living in Cranfield we cannot access any GP services without a fight. A disaster waiting to happen.
An opportunity did the area to lead the way in health care! Grab it to see it rise as a desirable area to live and work.
Great to see the CCG engaging in this way
Keep up the amazing work, thank you to everyone.
Thank you for the opportunity to be able to take part, I didn't know about the consultation until advised at work yesterday. I work for Luton Council.
well done, I thought the documentation was very accessible, easy to understand and very well presented
Q13: Local Authorities and local issues
All of this is great but living in Cranfield we cannot access any GP services without a fight. A disaster waiting to happen.
As the demographics are so different in the 3 areas aligning services will be difficult.
Don't understand why MK has been linked with Luton - we were always linked with Northampton general hospital in the past
Health services should be appropriately funded for all across BLMK to promote the health and fertility of everyone.
I live on the border of Cambs and Herts - and my first choices of hospitals are Lister (Stevenage) or Addenbrookes/Rosie/Papworth (Cambridge) - what is being done to align the policies across these areas?
I see no need to have different services in Luton and Milton Keynes vs Bedford Borough
Whilst I recognise that that the new CCG needs to review services across the area, I would caution the wholesale reduction of services that this consultation seems to outline. As a resident of Luton, it seems that Luton is paying the price for the merger. I would like to remind the CCG that Luton is different to the rest of Bedfordshire and to a certain extent Milton Keynes. It was because of these differences, that Luton became a Unitary authority and separated from Bedfordshire and thus had its own CCG. Please consider that when you are reviewing services - we are not all the same!
Q13: Insufficient advertising of the consultation
I have only just seen this survey advertised on Facebook .I suppose if the public dont know about a survey then decisions are easier to be dealt with .
It was very poorly advertised. I was only made aware when sitting in my gp surgery waiting for my flu jab
Not advertised well.
Thank you for the opportunity to be able to take part, I didn't know about the consultation until advised at work yesterday. I work for Luton Council.
Q13: Response options limited
in the future try and be a bit less black and white, why do we always have to be one or the other? always taking away and making everything the lowest common denominator, how about a bit of compromise? making it slightly worse for some and slightly better for others. At least look at it and cost it up too.
It appears you have deliberately limited the choice of options available within the consultation. With a little bit more thought, I'm sure additional options could have been accommodated.
the choices to respond were limited
The lack of options is disappointing and deliberately limits the opportunity of residents to inform decision making.
When the CCG was set up we were told that it would improve health services across Bedfordshire providing more specialist care not less. This consultation on 'alignment' appears to take the lowest common denominator as the preferred option rather than thinking creatively about solutions. It is extraordinary to have only 2 options presented purely on cost basis with no argument about health care.

Q13: Problems with online and e-mail
Consultation questionnaire difficult to complete online - pages keep moving involuntarily
I could not find a specific email address to send my comments in full. I do not believe this is a consultation. Representations are most likely to be ignored as you have already made up your minds.
without knowing the next question, this question is in the wrong place
Q9: Other
(NB sometimes these comments are duplicated elsewhere, if part of the comment falls into another category; they have been placed here because another part of the comment cannot be placed under a main category)
For this question, this category is the most diverse, as there were many single comments that did not fit into anything other than their own category.
Consider drugs and all other addiction treatments into health budgets as it is a major problem in our area
I feel people/public should depend less on the state to provide everything! The NHS is not going to last long at this rate.
I oppose any cutting of health services. I oppose these health services being privatised.
Its important that all services are identical
No
The NHS will never provide an efficient, high quality, customer focused service while it remains a state monopoly. There is a need for a profit motive to provide efficiency and competition with consumer freedom of choice to provide high quality. GP's and pharmacies should be taken out of NHS control as a start.
The real issue facing the NHS is its apparently infinite capacity to absorb money without producing commensurate results. (Eg in last 10 years, 40% increase in budget, 180,000 more staff, yet falling apart at the seams.) Until that matter is addressed effectively you are merely rearranging the Titanic's deckchairs.
There should be more opportunity for the public to have a say in which services are provided by the GPs and which are not. E.g. aspirin on prescription is not necessary.
Use the money to invest in prevention and comprehensive view of patient care. If you work on prevention you will save money in the long run, it doesn't always have to be wait for someone to be really sick to care about them. So often people are misdiagnosed simply because GPs don't review patient files and don't connect the dots on symptoms leading to something bigger.
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With all due respect, shouldn't we be following NICE guidelines as the national standard. There shouldn't be a postcode lottery for healthcare.