THIS MEETING WAS NOT QUORATE

Berkshire West Clinical Commissioning Group
Buckinghamshire Clinical Commissioning Group
East Berkshire Clinical Commissioning Group
Oxfordshire Clinical Commissioning Group

Thames Valley Priorities Committee

Minutes of the meeting held Wednesday 26th September 2018

Conference Room, Jubilee House, 5510 John Smith Drive, Oxford OX4 2LH

Alan Penn	Lay Member Chair	Thames Valley Priorities Committee
Dr Miles Carter	West Oxford Locality Clinical Director	Oxfordshire CCG
Linda Collins	Clinical Effectiveness Manager (CCG)	Oxfordshire CCG
Edward Haxton	Deputy Finance Director	Berkshire West CCG
Andrew McLaren	Deputy Medical Director	Buckinghamshire NHS Trust
Robert Majilton (via telephone – part)	Deputy Chief Officer	Buckinghamshire CCG
Dr Matt Mayer	LMC Chief Executive	Berkshire, Buckinghamshire & Oxfordshire
Dr Jacky Payne	GP	Berkshire West CCG
Dr Raju Reddy	Secondary Care Consultant	Berkshire West CCG
Sarah Robson	Head of IFR	SCW
Dr Mark Sheehan (part)	Special Advisor – Ethics	University of Oxford
Bhulesh Vadher	Clinical Director of Pharmacy and Medicines Management	Oxford University Hospital NHS Foundation Trust

In Attendance:

Tiina Korhonen	Clinical Effectiveness Lead	SCW
Kathryn Markey	Clinical Effectiveness Manager	SCW
Katie Newens	Clinical Effectiveness Researcher	SCW
Rachel Finch	Clinical Effectiveness Administrator – Minute Taker	SCW

Topic Specialists in Attendance for Agenda Items:

Item 6 – Evidence Review: Iron chelation for myelodysplastic syndromes		
Alex Sternberg	Consultant Haematologist; Thames Valley network co-lead for Myelodysplastic Syndromes,	Oxford University Hospitals Foundation Trust and Great Western Hospitals Foundation Trust
Item 7 – Evidence Review: Preservation of fertility		
Fatima Husain	Consultant in Obstetrics & Gynaecology; Lead for Fertility & FGM	Frimley Health Foundation Trust
Parveen Sharma	Equalities and Diversity Senior Manager	SCW
Alex Sternberg	Consultant Haematologist	Oxford University Hospitals Foundation Trust and Great Western Hospitals Foundation Trust

THIS MEETING WAS NOT QUORATE

Item 8 – Evidence Review: Primary care fertility pathway		
Dr Lalitha Iyer	Medical Director & Women's Health Lead	East Berkshire CCG
Fatima Husain	Consultant in Obstetrics & Gynaecology; Lead for Fertility & FGM	Frimley Health Foundation Trust

Apologies:

Lindsey Barker (LB)	Medical Director	Royal Berkshire NHS Foundation Trust
Francis Fairman	Assistant Director – Clinical Strategy	NHS England (TV area)
Dr Mark Hancock	Medical Director	Oxford Health NHS Foundation Trust
Dr Graham Jackson	Clinical Chair	Buckinghamshire ICS Clinical Lead
Dr Megan John	GP, Berkshire East CCG Lead	East Berkshire CCG
Tessa Lindfield	Strategic Director for Public Health	Berkshire
Tracey Marriott	Director of Innovation Adoption	Oxford Academic Health Science Network
Chris Newdick	Professor of Health Law	University of Reading
Amaka Scott	Commissioning Interfacing Pharmacist	Berkshire West CCG
Dr Karen West	Clinical Director Innovation	Buckinghamshire CCG

1.	**Welcome & Introductions**
1.1	The Chair opened the meeting and welcomed the members of the Committee.
2.	**Apologies for Absence**
2.1	Apologies recorded as above.
2.2	The meeting of 25th July 2018 was not quorate. **Action: Clinical Effectiveness team to circulate minutes detailing any policy recommendations made by the Committee to absent members for approval.** Post meeting note: Tessa Linfield, Strategic Director of Public Health, Berkshire has agreed the minutes.
3.0	**Declarations of Interest**
3.1	None were declared.
4.	**Draft Minutes of the Priorities Committee meeting held 25th July 2018 - Confirm Accuracy**
4.1	**The draft minutes were accepted as a true record of the meeting.**
5.	**Draft Minutes of the Priorities Committee meetings – Matters Arising**
5.1	**Minutes of the Priorities Committee held in May 2016, Action 10.1 – Fertility care pathway** - **September 2017 Update:** A working group has been formed; an initial meeting is being arranged. **November 2017 Update:** Two GPs, from Berkshire East and Berkshire West are looking at the primary care fertility pathway; they will consult with clinicians from all of the relevant localities to produce a final draft. A report will be presented to this Committee, provisionally in March 2018. **May 2018 Update: Minutes of the Priorities Committee held in May 2018 – Action 8.2 - Paper 18-003a & 18-003b – Fertility Care Pathway for Primary Care** The attending clinicians to provide an Evidence Review: Primary Care referral into Secondary Care for Couples with Infertility to include the Pathway and present to the Committee for consideration at the 25th July 2018 TVPC Meeting **July 2018 Update:** An agenda item for 26th September meeting - **Refer to agenda item 8**
5.2	**Minutes of the Priorities Committee held in March 2018 – Action 3.2 – Non-quorate Committee Meeting of 24th January reference Paper 17-026 Draft Policy Review: Flash Glucose Monitoring System (FGS) and proposed Patient Agreement Forms** JB to contact each TVPC CCG representative to discuss and agree the audit criteria and time frame to monitor the use of FGS. **May 2018 Update:** JB to provide an update at the July 2018 meeting. **July 2018 Update:** Action carried forward to September 2018 meeting **September 2018 Update:** To be brought back to Committee when audit criteria from CCGs are available. **ACTION Closed**
5.3	**Minutes of the Priorities Committee held in March 2018 – Action 7.1 – Evidence Review: Iron Chelation for Myelodysplastic Syndromes** Time constraints within the March meeting prevented the evidence review of Iron Chelation for Myelodysplastic Syndromes being presented to the Committee; this item was deferred to the 23rd May 2018 meeting. **May 2018 Update:** Due to other priority items on the May agenda Iron Chelation has been deferred to 25th July 2018 meeting. **July 2018 Update:** An agenda item for September 2018 meeting – **Refer to agenda item 6**
5.4	**Minutes of the Priorities Committee held in May 2018 – Action 9.1 - Paper 18-004 & 13-016: Preservation of Fertility policy TVPC17 revisit** The Clinical Effectiveness team to provide an Evidence Review: Preservation of Fertility, for consideration by the Committee at the 26th September 2018 meeting **– Refer to agenda item 7**
5.5	**Minutes of the Priorities Committee held in July 2018 – Action 5.8.1 – Matters Arising: Paper 17-041 - Use of Biological and Immunomodulatory Therapies in RA** The Clinical Effectiveness team to update the draft policy recommendation: Use of Biological and immunomodulatory therapies in Rheumatoid Arthritis and circulate to CCG representatives for comment. Comments to be received within the 2 week feedback period following issue.

	ACTION Complete
5.6	**Minutes of the Priorities Committee held in July 2018 – Action 6.6 - Paper 18-006 – Evidence Review: Sequential use and dose escalation of biologics in Crohn's disease** **6.6.1** Clinical Effectiveness team to check Oxfordshire CCG cost data. **ACTION Complete**
	6.6.2 Clinical Effectiveness team to ask the specialist clinicians to develop a policy and pathway for the sequential use of biologics in Crohn's disease with their colleagues from Oxford, Reading, Buckinghamshire and Frimley. The Committee suggested this may be presented to the 26th September TVPC meeting. **September 2018 Update:** Specialist clinician is meeting with colleagues in early October to commence the policy and pathway development process. Committee to be updated at 28th November meeting.
	6.6.3 Clinical Effectiveness team to recommend withdrawal of MOBB Statement: Dose escalation therapy with infliximab and adalimumab in children (aged 6-17 years) with severe active Crohn's disease to the CCG governing bodies. **ACTION** Will be completed when new policy is developed.
5.7	**Minutes of the Priorities Committee held in July 2018 – Action 7.6 - Paper 18-007 - Evidence Review: Topical negative pressure for wound therapy (NPWT); vacuum-assisted wound closure dressings** The Committee considered the evidence provided and felt that more information was required before a policy recommendation could be drafted. The Clinical Effectiveness team were asked to review the patient population for diabetic foot ulcers and provide further local data and financial impact for review at the next meeting on 26th September 2018: **7.6.1.** Provide the Committee with details of the nature of the original request for the evidence review. Post meeting note added and circulated as part of July 2018 minutes**.** **ACTION Complete**
	7.6.2. Obtain community level data for the numbers of patients in the TVPC locality currently being treated for diabetic foot ulcers. **7.6.3**. If available, obtain data re. current spend for treatment of diabetic foot ulcers and projected spend should NWPT be commonly adopted for this indication **7.6.4**. Obtain data regarding reduction in bed days for patients discharged from the acute sector with NPWT and potential associated reduction in cost. **7.6.5**. NPWT to be added as an agenda item for consideration at the 26th September TVPC meeting **September 2018 Update:** Committee requested further cost impact review of using NPWT for diabetic foot ulcer and in particular impact on for length of stay; some work has been done in estimating the number of patients as well as the activity and cost for in-patient treatments. However, it is not possible to speculate out of all of these patients with diabetic leg ulcer who would be suitable for NPWT and how many are actually currently having the treatment. Accurate data on current use is not readily available. SCW analytics confirm that any procedure and treatment related to surgery as an in-patient is within tariff.
14.20hrs	**Robert Majilton joined the meeting via telephone**
	The Committee acknowledged the lack of accurate local data and evolving evidence base. However, it was noted that a local policy may be helpful in supporting the monitoring of the use of NPWT, therefore further exploration of the data would be helpful. **ACTION: CE team further review the data and refresh the paper to put forward a recommendation to the Committee at 28th November meeting.** Post meeting note: November agenda discussed with the Chair. Agenda is full and dedicated to orthopaedic topics with clinical representation already secured, therefore agreed to defer NPWT until January Committee.

5.8	**Minutes of the Priorities Committee held in July 2018 – Action 8.1 - Paper 18-008 – Current policies update** The Clinical Effectiveness (CE) team presented the Committee with the first tranche of policies reviewed under the Policy Update Programme to ensure policies are still relevant, take into account the latest guidance and reflect up to date clinical and cost-effectiveness research. **8.1.1** CE team to update links and include new guidance where appropriate for the following policies: Ethical Framework; TVPC3; TVPC19; TVPC21 & TVPC32 **ACTION Complete** **8.1.2** If not already identified as items for review on the TVPC work programme the CE team to include policy items TVPC5, TVPC12; TVPC14; TVPC17 & TVPC22 as requiring review to the Committee work programme. **ACTION Complete** **8.1.3** The CE team to add procedure (OPCS) codes to existing TVPC policies being updated. **ACTION Complete** **8.1.4** The CE team to add review of the Ethical Framework as an item for discussion at the TVPC training session on 28th November 2018. **ACTION Complete**
5.9	**Minutes of the Priorities Committee held in July 2018 – Action 9.1 – National evidence based interventions (EBI) programme consultation.** **9.1.1** TVPC Committee members are to provide their response to the EBI consultation to the Clinical Effectiveness team by 24th August 2018. **ACTION Complete**
	9.1.2 Clinical Effectiveness team to collate TVPC CCG EBI consultation comments and co-ordinate a joint draft response. Draft joint consultation response to be circulated for comment in mid-September; comments to be returned to CE team in readiness for final sign off at the TVPC meeting of 26th September. **September 2018 Update:** Of the 17 policies NHS England is putting forward and consulting on, 4 are not normally funded proposals, and the remaining 13 are threshold policies. The CE team collated Committee responses, details provided in paper 18-010a issued as part of the meeting pack. The consultation closes on Friday 28th September. Any further comments were invited from the Committee. Further comment noted from RR to emphasize that it will be critically important to have clear communication at the time of distribution and publication of the policies, to ensure the difference of not normally funded and threshold policies is understood by all, patients and clinicians, to avoid confusion and unnecessary work. **ACTION: Clinical Effectiveness team to add a point highlighting the need for clear communication to the TVPC CCG EBI joint consultation response document before submitting to NHSE on behalf of the Committee.**
5.10	**Minutes of the Priorities Committee held in July 2018 – Action 11.1 – AOB - Evaluation Form.** Clinical Effectiveness team to provide an evaluation form to Committee members with the minutes for completion and return at the 26th September meeting (hard copy will also be provided at the meeting as necessary). **ACTION Complete**
5.11	**Minutes of the Priorities Committee held in July 2018 – Action 11.2 – AOB – Aesthetic treatments for adults and children** Clinical Effectiveness team to draft an update to TVPC16 Aesthetic treatments for adults and children policy and circulate for comment. Comments to be received within the two week feedback period following issue. **ACTION Complete**
5.12	**Minutes of the Priorities Committee held in July 2018 – Action 11.3 – AOB – TVPC66 NICE 'do not do' policy** Clinical Effectiveness team to prepare papers to CCGs recommending withdrawal of TVPC66 NICE 'do not do' policy. **ACTION Complete**
5.13	**Minutes of the Priorities Committee held in July 2018 – Action 11.4 – AOB – Venue for 28th November training session and Committee meeting** Clinical Effectiveness team to confirm to Professor Chris Newdick of Committee acceptance of his offer of Reading University as a venue for both the TVPC training event and TVC meeting on 28th November 2018. **ACTION Complete**

14:30hrs	Robert Majilton left the meeting as unable to follow conversation clearly or contribute; comments on papers for discussion during the meeting were forwarded to CE team.
6.	**Paper 18-011 & 18-011a – Evidence Review: Iron chelation for myelodysplastic syndromes**
6.1	Thames Valley Clinical Commissioning Groups (TVCCGs) requested a review of the use of iron chelation therapy (ICT) in the management of Myelodysplastic syndrome (MDS). NHS England transferred the commissioning responsibility to CCGs in 2015. It was therefore suggested that TVCCGs may wish to produce their own commissioning statement. There is currently one policy relating to iron chelation for MDS within TV CCGs. This is for Buckinghamshire/ Milton Keynes dated 2007: Deferasirox in the management of iron overload stating that its use in patients with myelodysplastic syndromes should be considered a low priority treatment. MDS are a group of malignant haematopoietic disorders with a variable progression to acute myeloid leukaemia (AML). The bone marrow makes abnormal cells that are not fully developed. The incidence reported of MDS nationally is approximately 4/100,000 population per year. It is predominantly a disease of the elderly with an incidence of >30/100,000 per year over the age of 70 years. MDS is considered a rare or 'orphan' malignancy. At the point of diagnosis, consideration should be given to the prognosis of the patient. The revised International Prognostic Scoring System (IPSS-R) categorises the risk as very low, low, intermediate, high and very high risk, with clear differences in overall survival and risk of progression to AML. Blood transfusions may be needed to improve symptomatic anaemia which leads to iron overload. In the UK there are currently three iron chelating agents two of which are licensed for iron overload in MDS: desferrioxamine (Desferal) and deferasirox (Exjade) when desferrioxamine is contraindicated or inadequate.
6.2	There are a number of national guidelines; the Scottish Medicines Consortium has recently accepted deferasirox for restricted use in MDS with an IPSS score of low or intermediate. The National Cancer Network also states that iron chelation therapy should be considered in patients who have received more than 20 to 30 red blood cell transfusions particularly in patients with low or intermediate IPSS scores. The British Society for Haematology (2014) states that iron chelation therapy cannot be routinely recommended for MDS patients with transfusional iron overload however consideration may be given to chelation therapy for patients with very good prognosis and triggers for iron chelation may be more than 20 units of red cells transfused and serum ferritin >1000µ/l in patients for whom continuing red cell transfusion is predicted. The East of England Priorities Advisory Committee concluded that there was insufficient evidence to routinely recommend the use of iron chelation, however in patients considered to have a low risk an application may be made through the IFR process for treatment. The Thames Valley Strategic Cancer Network guidelines state that ICT should be considered for patients on a regular red cell transfusion programme who have a prognosis of greater than 2 years (IPSS-R score of 3.0 or less). In addition consider chelation therapy in patients with higher risk forms of MDS who are undergoing transplant.
6.3	A Cochrane review (2014), with an objective of analysing the cost effectiveness of deferasirox in MDS concluded that there were no randomised control trials (RCTs) and that guidelines available were not based on high quality evidence. There is one RCT awaiting results. All the available studies found were observational and analyses of registry data. Conclusions

	from these included that patients with MDS, International Prognostic Scoring System (IPSS) low- or intermediate-1-risk who received iron chelation therapy (ICT), experienced greater overall survival, cardiac event-free survival and a higher proportion of other favourable outcomes compared with patients who did not receive ICT. One observational study found of high risk patients with transplant concluded that low dose deferasirox is an effective chelation therapy after stem cell transplant.
6.4	For 2017-2018 data obtained from Royal Berkshire FT and Oxford University Hospital, expenditure on deferasirox for clinical haematology and medical oncology specialities was approximately £83,000. Frimley and Buckinghamshire did not report that they were using deferasirox. No expenditure was reported for desferrioxamine. The clinical specialist advised that there would be approximately 10 patients per year across Thames Valley with low risk MDS that would require iron chelation and potentially 2 patients per year with high risk MDS undergoing stem cell transplant who would require iron chelation.
6.5	Discussion with the specialist in attendance raised the following points: ICT is used in the management of patients with thalassemia, an inherited blood disorder where a patient is genetically unable to make red blood cells. Blood transfusions increase the iron levels and this can damage the heart and other organs. There are relatively good data that indicates that patients with thalassemia that are well chelated have better outcomes than patients who are not. It is plausible that the same effect can be seen in patients with low risk MDS. The reason low risk groups of patients with MDS have been included in the national guidelines and Thames Valley Strategic Clinical Network guidelines, is that these patients most resemble the thalassemia patients. A transfusion patient with MDS is regarded as a failed patient. Other treatments are used initially to try and prevent a patient from receiving blood transfusions. A transfusion programme is also associated with high costs. It is unlikely that iron chelation alone will result in large additional costs to the overall cost of treating these patients. Decision to chelate would be through a multi-disciplinary team (MDT). Locally this approach is robust and well regarded.
6.6	The Committee reviewed the evidence, the Thames Valley Strategic Clinical Network guidelines, regional policies and national guidelines. The Committee agreed to recommend guidelines for Thames Valley CCGs for the use of iron chelation in the management of Myelodysplastic syndrome. The Committee agreed that iron chelation therapy may be considered for: • patients on a regular red cell transfusion programme who have a prognosis of greater than 2 years (IPSS-R score of 3.0 or less). This will include patients with red cell predominant MDS (i.e. RA RARS or del 5(q)) after they have received ~25 units of red cells and whose serum ferritin is greater than 1000 mcg/L. • Patients with higher risk MDS who are eligible for a stem cell transplant. Any decision to treat iron chelate a patient (low or high risk) with iron chelation therapy should be made as part of a MDT treatment decision. **ACTION: The Clinical Effectiveness team to draft a policy recommendation: Iron chelation for myelodysplastic syndrome (MDS) and circulate for comment. Comments to be received within the 2 week feedback period following issue.**
7.	**Paper 18-012 - Policy Review: Preservation of fertility**
7.1	Fertility preservation involves freezing and storing gametes i.e sperm or eggs (oocytes), or embryos for use in a person's future fertility treatment. Thames Valley Clinical Commissioning Groups (TVCCGs) have currently a joint (2015) policy in place for the preservation of fertility. This policy relates to the preservation of gametes and embryos in post-pubertal patients, in advance of chemotherapy or radiotherapy treatment for cancer that carries a high risk of infertility. Currently other applications for preservation of fertility are considered through the

	CCGs' Individual Funding Request (IFR) process. TV CCGs also have a standalone policy statement for gender dysphoria regarding the specialised commissioning responsibility (core-procedures) which states that 'non-core procedures' are not normally funded by CCGs and the application for gametes storage is via IFR. A third related policy across TV is a TVPC policy statement for assisted reproduction services for infertile couples. Local issues have been noted in relation to the preservation of fertility policy and the Equalities Act 2010 in view of omitting other patients other than those with cancer from the current policy. In August 2018 NHS England received a challenge from the Human Rights Commission on the grounds of excluding gender dysphoria patients from normally funding their gamete storage. The Clinical Effectiveness team has been advised by NHS England to pursue local policy review as the commissioning responsibility for storage of gametes for gender dysphoria patients is expected to remain with the CCGs. There has been a consultation on the NHS England gender dysphoria policy, which closed October 2017, but the outcome is still pending. There is significant variation nationally and regionally in CCG approaches to preservation of fertility. The Committee is asked to: • Consider whether the current policy for preservation of fertility should be revised to include patients who receive other medical treatments and interventions which may carry a high risk of infertility, such as patients undergoing gender reassignment and patients receiving treatment for non-cancer indications. • Ensure that all three policies are aligned and cross referenced.
7.2	Non-oncological medical causes of infertility include: • Genetic conditions (such as Turner mosaicism, fragile X syndrome (FMR1) carrier status or galactosaemia) that carry a risk of non-treatment related premature ovarian insufficiency (POI). • Medical conditions requiring gonadotoxic therapy that may compromise fertility potential; such as cyclophosphamide for systemic lupus erythematosus and bone marrow transplantation or stem cell transplantation for benign haematological diseases such as sickle cell anaemia and thalassemia, and inflammatory bowel disease. • Surgical therapies for benign gynaecological conditions, such as surgery for endometriomas, large ovarian dermoid cysts and recurrent benign ovarian cysts can reduce ovarian reserve. • Hormone treatment and genital surgery for gender dysphoria. The current numbers of IFR requests for these patients across the TVCCGs are low, less than 10 per year. The attending haematologist confirmed that for his speciality the patients requiring gonadotoxic treatment is very low, possibly one or two per year at the most. Feedback from gastroenterologist advises on similarly low numbers. In view of repeat gynaecological surgery impacting on ovarian reserve, the attending clinician estimated that in a population of 250,000 approximately 5 patients per year may be affected. The attending clinician also advised that Turner mosaicism and Fragile X syndrome are both inherited conditions and currently numbers suitable for cryopreservation would be very low. The British Fertility Society policy and practice guideline (2018) - 'Fertility preservation for medical reasons in girls and women' notes that; at present, strategies for fertility preservation in post-pubertal girls who are at risk of premature ovarian insufficiency (POI) due to chromosomal, genetic or metabolic conditions may be limited to ovarian tissue transplant, alone or in combination with immature oocyte collection from the tissue followed by in vitro maturation and vitrification of mature oocytes. Ovarian tissue transplant is currently still considered to be an experimental treatment.

	Regarding the gender dysphoria population, it is anticipated that numbers of patients with gender dysphoria seeking treatment will increase, in particular in the younger age group. The Gender Identity Research and Education Society (GIRES) report (2011 update) notes that current growth in the number of gender variant people presenting for treatment may continue for a lengthy period, as more gender variant people feel able or compelled to present to health professionals with gender dysphoria. There is little data on the future use of cryopreserved material. Currently the number of women having treatment using frozen eggs is still low. Locally, in terms of the current approvals for cryopreservation for patients affected by cancer in the last 2 yrs and 9 months, data indicated that 24 applications were agreed. The estimated annual spend is approximately £28,000 for first year storage for new patients across TV CCGs, with on-going storage for initial five years, total of £39,800 at year five.
7.3	Equality and Human Rights Commission - Gender Reassignment Discrimination (Last updated: 11 Aug 2017) outlines two types of discrimination particularly relating to current policy review; direct discrimination occurs when an individual is treated worse than another individual in a similar situation because they are transsexual. Indirect discrimination occurs when an organisation has a particular policy or way of working that puts transsexual people at a disadvantage. Sometimes indirect gender assignment discrimination can be permitted if the organisation or employer is able to demonstrate that there is a good reason for the discrimination. This is known as objective justification. The attending Equalities and Diversity Lead clarified the case for the objective justification. A policy which excludes certain people must be justified because there is an objective business justification for doing so. In this scenario there are at least 3 reasons which could be put forward for objective justification: • Financial pressures: CCGs have a statutory duty to consider. CCGs may prioritise their limited resource to impact the maximum number of people. If comparing it with cancer patients who are currently able to seek cryopreservation then there are likely to be much higher numbers of cancer patients than people with gender dysphoria seeking treatment. • National priorities: cancer is a national priority therefore CCGs may justify it on grounds of meeting national priority and therefore it may be reasonable to limit access to treatment to certain groups of people. • The system for application for funding via CCGs' IFR process is open to treatments or groups of patients 'not normally funded'. However, whether the objective justification outlined by the CCG is seen to be non-discriminatory can only be decided by the courts. CCGs will run the risk of legal challenge even when they have clearly stated business rationale for having a differential policy for patients with cancer and patients with gender dysphoria or other conditions. The attending Consultant in Obstetrics and Gynaecology raised the issue of the current cryopreservation age limit for females at harvesting of eggs being under 35 years, which is similar to the threshold for assisted conception services policy. Suggestion was put forward that the age limit could be raised to 39 to 40 years for the cryopreservation for cancer treatment in order to make the guideline fairer. The current policy commits the CCGs to offering continued storage of oocytes and embryos for an initial period of 5 years, with opportunity for renewal for a further 5 years or up until the patient's 42nd birthday. The Committee did note that the assisted conception policy age threshold is based on the ability to conceive, as after the age of 35 it decreases rapidly.

7.4.	The Committee had a lengthy debate covering the potential options for future policy: Option 1. Maintain current policy if satisfied that the CCGs are not in breach of the Equality Act. (and Public Sector Equality Duty). Option 2. Consider not funding preservation of fertility for any medical or social indication. This would constitute a departure from NICE Clinical Guideline recommendations for preservation of fertility in advance of cancer treatment. This would also require decommissioning a service provision for the currently funded patient group and as such may require public consultation. Option 3. Agree to fund preservation of fertility for other medical indications as well as cancer, in advance of treatment or intervention that carries a high risk of infertility or for patients with conditions affecting fertility. The Committee was minded to agree that the case for objective justification may not be strong and in view of the equality legislation and still risks a legal challenge. The Committee considered the Option 3. If the funding was agreed for other conditions as well as cancer it was suggested that an option was to consider a 'standard of risk' i.e. estimated level of risk of infertility. However, it was acknowledged that finding a risk threshold would be very complex and involve funding on going tests. An additional point was raised that it is important to articulate in the policy that the CCG does not necessarily guarantee funding of assisted conception later and does not fund surrogacy. It was noted that the population for non-oncological medical causes of infertility other than gender dysphoria is relatively small and stable. However, the gender dysphoria population and its diversity across CCG populations is more difficult to estimate. The Committee noted the local population estimates and projected costs of cryopreservation over five years as per current policy (assumptions outlined in the review paper). The estimated cumulative cost could be up to £1 million per year at year five and onwards across the TV CCGs. The new activity and cost would be additional to current cryopreservation cost for cancer patients.
7.5	The Committee agreed to progress with Option 3 to fund the preservation of fertility for other medical indications as well as cancer in advance of treatment or intervention that carries a high risk of infertility or for patients with conditions affecting fertility. The policy should include the current thresholds plus the following criteria: • a plan to review the policy in two years • assisted conception will only be funded if the patients meets the relevant current policy • surrogacy will not be funded • funding for medical reasons only **ACTION: The Clinical Effectiveness team to draft a policy recommendation: Preservation of fertility and circulate for comment. Comments to be received within the 2 week feedback period following issue.**
8.	**Paper 18-013 - Evidence Review: Primary care fertility pathway**
8.1	LI apologised for the delay in sending papers to the Committee. The reason for reviewing the TV primary care fertility pathway is to unify and streamline the guidelines for primary care management of sub fertility across the CCGs. The aim is to make sure that in primary care the patients are adequately investigated, referred appropriately and in a timely manner to secondary care, as well as to avoid duplication of tests carried out. The discussion is a continuation from the pathways presented to the Committee in May 2018.
8.2	The timing of investigations was discussed. The proposed pathway suggests investigating patients in primary care when they present after one year of trying to conceive whereas the joint assisted reproduction services policy states that couples should have tried for at least two years before they can be referred to interventions. It was proposed that if a patient comes to a GP in primary care it would be appropriate to offer initial investigations after one year as per

	NICE advice. If there are 'red flags' and if there are any clinical concerns then the patient can be referred to secondary care. Reassurance can be offered if investigations do not raise concerns. A point raised by the Committee in May was that a patient is not necessarily referred to secondary care just for investigations but also for advice and guidance. NICE guidelines note that it is the consultant's responsibility to decide whether the patient needs IVF or not. With regards to BMI; the assisted reproduction services for infertile couples policy threshold is BMI 19 to 29.9 inclusive for women. The draft pathway notes that patients with BMI up to 35 can be referred to secondary care. The justification for this is that between BMI 30 and 35 investigations can still be performed, such as tubal testing, and it allows time to for necessary tests and potential interventions. The patient is informed as early as possible of the assisted conception threshold, rather than at the end of the pathway. Smoking advice was discussed, including the point that the patient is also supported to stop using nicotine replacement products. The current assisted conception policy threshold notes that the couple should be non-smokers for at least 6 months. Current practice supports this position and GPs can refer patients to smoking cessation services. In terms of the age when to stop referring to secondary care, the attending clinicians acknowledged the evidence that demonstrates how fertility and conception rates decline quite sharply after the age of 35 and that after 42 the curve is a steep decline. It is proposed that women over 42 years need not be referred. The ability to refer until 42 years offers opportunities for assessment and to address ovulation problems (25% of patients) and secondary sub-fertility, which is more common in late 30s, where interventions such as tubal surgery can be offered. The Committee noted that the cost impact of the proposed pathway was not outlined. It was noted that the similar primary care pathways are already in place across the CCGs, with slightly differing processes. The proposed pathway offers alignment across TVCCGs and in practice may offer savings in reducing duplication of tests and stopping unnecessary referral to secondary care. The Committee agreed that for the proposed East Berkshire pathway to be issued to TVPC CCG representatives for comment. Specialist clinicians will finalise the draft pathway, provide a cover sheet highlighting the differences and identifying the implications of the changes. A copy is to be provided to the Clinical Effectiveness team for circulation with the other draft policies. **ACTION: Specialist Clinicians to provide the Clinical Effectiveness team draft recommendation Primary Care Referral Pathway for Subfertility. Clinical Effectiveness team to circulate for comment. Comments to be received within the 2 week feedback period following issue.**
9.	**Paper 18-014 - Clinical Policy Review: Policy Update Programme**
9.1	Time constraints prevented the policies identified for review being discussed; this item is deferred to 28th November 2018 meeting.
10.	**Paper 18-015 - Horizon Scanning**
10.1	Time constraints prevented review of the horizon scanning September update paper; this item is deferred to 28th November 2018 meeting.

THIS MEETING WAS NOT QUORATE

11.	**Paper 18-016: Standard Operating Procedures (SoP) and Paper 18-017: Terms of Reference (ToR)**
11.1	Time constraints prevented review of these papers. ***Post meeting note: ACTION: Clinical Effectiveness team to issue SoP and ToR highlighting their suggested minor changes with the draft minutes of this meeting for comment. Comments to be received within the 2 week feedback period following issue.***
12.	**Any Other Business**
	2019-20 Work Programme Workshop Monday 5th November
12.1	A reminder to CCG representatives to submit their topics for the consideration of the next year's work programme to the Clinical Effectiveness email box by Wednesday 17th October. The Workshop will take place Monday 5th November in Jubilee House, Oxford.
13.	**Next meeting**
	The next meeting with a pre meeting training session will be **Wednesday 28h November 2018, to be held in the Cedar Conference Room, Whiteknights Campus, and University of Reading RG6 6UR.** **Training session 11:30 - 13:30 followed by lunch (provided) and Committee meeting 14:00 - 16:30.**
14.	**Meeting Close**
	The Chair thanked everyone for their contributions to the discussions and closed the meeting.