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

Thames Valley Priorities Committee (Interim)

Minutes of the meeting held Tuesday 24th June 2020

On-line via Microsoft Teams

Alan Penn	Lay Member Chair	Thames Valley Priorities Committee
Jane Butterworth	Assistant Director Medicines Optimisation	Buckinghamshire CCG
Linda Collins	Clinical Effectiveness Manager (CCG)	Oxfordshire CCG
Edward Haxton	Deputy Finance Director	Berkshire West CCG
Dr Megan John	GP, East Berkshire CCG Lead	East Berkshire CCG
Catriona Khetyar	Head of Medicines Optimisation	East Berkshire CCG
Professor Chris Newdick	Special Advisor - Law	University of Reading
Dr Jacky Payne (Part)	GP	Berkshire West CCG
Dr Raju Reddy	Secondary Care Consultant	Berkshire West CCG
Dr Mark Sheehan	Special Advisor - Ethics	University of Oxford
Dr Karen West	Clinical Director Integration	Buckinghamshire CCG

In Attendance:

Kathryn Markey	Clinical Effectiveness Manager	SCW
Tiina Korhonen (Part)	Clinical Effectiveness Manager	SCW
Jenny Kovalaine-Kwan	Clinical Effectiveness Manager	SCW
Rebecca Hodge	Clinical Effectiveness Manager	SCW
Rachel Finch – Minute Taker	Clinical Effectiveness Administrator	SCW

Apologies:

David Pollock	Interface Lead Pharmacist	Berkshire West CCG

1.	**Welcome & Introductions**
1.1	The Chair opened the meeting, welcomed the Committee members and set out how the on-line meeting is to operate.
2.	**Apologies for Absence**
2.1	Apologies recorded as above.
3.0	**Declarations of Interest**
3.1	None declared.
4.	**Draft Minutes of the online 'Teams' Priorities Committee meeting held 19th May 2020 – Confirm Accuracy**
4.1	The draft minutes were accepted as a true record of the meeting.
5.	**Draft Minutes of the online 'Teams' Priorities Committee meeting – Matters Arising**
5.1	**Minutes of the Priorities Committee held online in May 2020 – Action 5.5 – Review RMOC Statement sequential use of biologic medicines – Paper 20-001** The Clinical Effectiveness (CE) team to draft a potential statement to be added onto each of the

5.1 Cont.	biologics policies advising that a 4th biologic or immunomodulatory drug will be funded if it possesses a mode of action previously not tried or if a patient has suffered an adverse drug reaction that necessitates discontinuation. The Committee to discuss this item further together with the financial impact and the development of a justification statement. **JUNE 2020 UPDATE:** Financial impact in progress. The CE team to bring back to the Committee in due course.
5.2	**Minutes of the Priorities Committee held online in May 2020 – Action 6.1 – Standard Operating Procedure (SOP)** The Clinical Effectiveness teams to update the SOP in line with the Committee's agreed recommended changes and submit to CCG Governing Bodies for their acceptance. **ACTION Complete**
5.3	**Minutes of the Priorities Committee held online in May 2020 – Action 7.1 – Ethical Framework (EF)** The Clinical Effectiveness team to update the EF in line with the Committee's agreed recommended changes and submit to CCG Governing Bodies for their acceptance. **ACTION Complete**
5.4	**Minutes of the Priorities Committee held online in May 2020 – Action 8.2 – System recovery post COVID-19** Oxfordshire CCG on behalf of Buckinghamshire, Oxfordshire and Berkshire West (BOB) Integrated Care System approached the chair, committee members and the Clinical Effectiveness team to assist providers and CCGs in developing strategies to prioritise patients and elective care as the system starts to recover post COVID-19. The Committee agreed that a sub group could be set up to scope this project. The Clinical Effectiveness team to organise a meeting of sub group. **ACTION Complete**
5.5	**Minutes of the Thames Valley Priorities Committee sub-group held June 2020 - System recovery post COVID-19** **ACTION: The Clinical Effectiveness team to update document: Principles for Prioritisation of Elective Care Patients document with details of the Chair, date and attendees.** The minutes were accepted as a true accuracy of the meeting. **ACTION: CN to provide wording regarding NHS waiting times to the Clinical Effectiveness team for inclusion in the System recovery post COVID-19 document prior to it being sent to Diane Hedges.** **ACTION: Clinical Effectiveness team to update the System recovery post COVID-19 Principles for Prioritisation of Elective Care Patients document to include comments from Chris Newdick and send to Diane Hedges for consideration and feedback with a copy to Committee members. Post meeting note: document with CH's comments has been circulated to Diane Hedges. Mark Sheehan has recirculated document to TVPC subgroup with further comments for feedback within 3 working days. Actions completed by 1st July 2020.**
6.	**Paper 20-006 Policy Update: Sodium oxybate for cataplexy and excessive daytime sleepiness in narcolepsy in adults**
6.1	Thames Valley Priorities Committee 'Policy Statement 112: Sodium oxybate for cataplexy (loss of voluntary muscle tone) and excessive daytime sleepiness in narcolepsy' has been in place for Berkshire West and East Berkshire CCGs since June 2007. It was considered to be a low priority treatment due to the limited evidence available in comparison to other treatments. A review of current guidance and evidence has been undertaken by the Clinical Effectiveness team under the policy updates programme.
6.2	In joint formularies sodium oxybate is a non-formulary drug in all TVPC CCGs except Oxfordshire where it is blacklisted but can be used via IFR by consultant neurologists. NHS England commissions sodium oxybate for children, the commissioning responsibility moves to CCGs for anyone aged 19 or over. Regional Medicines Optimisation Committee (RMOC) issued a statement in October 2019 which aims to address inconsistencies across England regarding access to sodium oxybate when a

6.2 Cont..	patient prescribed sodium oxybate as a child under NHS England arrangements then transitions to adulthood and CCG commissioning. NHS England Specialised Commissioning, together with NHS Improvement, are developing a framework for adult services clinicians to use. However they suggest that in the interim any adult patients with narcolepsy with cataplexy who have transitioned from paediatric care should continue to receive sodium oxybate. The RMOC statement does not stipulate that sodium oxybate should be commissioned for adults, but does aim to assist with the decision making process and make it more consistent.
6.3	Narcolepsy is a rare condition that causes a person to suddenly fall asleep at inappropriate times. Type 1 narcolepsy also features cataplexy. It has been estimated that only a sixth of patients receive pharmacological treatment for their condition. There is no cure for this condition, so although in some instances cataplexy may improve with age, most children treated under the NHS England criteria may require lifelong treatment. However, NHS England suggests that the cohort size is small, only around 10 paediatric patients per year nationally.
6.4	Evidence comparing sodium oxybate to other treatment options remains limited, there is only one randomised controlled trial (RCT) that is not placebo-controlled and compares sodium oxybate against an alternative treatment. In general, systematic reviews of RCTs indicate potential improvement of narcolepsy with cataplexy with sodium oxybate when compared to placebo. The Committee was provided with information for approximate annual cost per patient. It was noted that sodium oxybate is a final line treatment option for patients who have not responded to other medicines or experience intolerable adverse effects from them.
6.5	The Committee discussed that evidence for the use of sodium oxybate in adults was still very limited. The Committee also acknowledged the very limited cohort size of paediatric patients (who received sodium oxybate via NHS England funding) transitioning to adult services. The Committee members agreed that stopping a treatment (that was funded by NHS England) because a patient has turned 19 years old would be unreasonable.
6.6	Following discussion the Committee agreed the Clinical Effectiveness team to draft a policy recommendation for the use of sodium oxybate for narcolepsy with cataplexy in patients transitioning into adult services. The patients would continue to be reviewed based on the RMOC criteria. Due to limited comparative evidence for clinical and cost effectiveness, the use of sodium oxybate should continue to be not normally funded for other adult patients. **ACTION: Clinical Effectiveness team to draft a policy recommendation for the use of sodium oxybate for narcolepsy with cataplexy for patients transitioning into adult services. For other adult patients sodium oxybate is not normally funded. The draft policy recommendation is to be circulated for comment. Comments to be received within the 2 week period following issue.**
7.	**Paper 20-007 – Policy Update: Intravenous versus oral steroids for exacerbations of multiple sclerosis**
7.1	Policy recommendation 67: Intravenous versus oral steroids for exacerbations of multiple sclerosis (MS) has been in place since 2012 and was identified for review under the policy update programme. The policy is currently held by Berkshire West, East Berkshire and Buckinghamshire CCGs. This recommends funding for oral steroids for exacerbations for MS as the evidence did not support the superiority of either oral or intravenous (IV) delivery. Oxfordshire CCG does not currently hold a commissioning policy. There are different joint formulary positions: Oxfordshire joint formulary states that methylprednisolone is suitable for continuation in primary care following specialist initiation. East Berkshire joint formulary classifies methylprednisolone as red drug, prescribed by hospital clinicians only, when IV. Berkshire West joint formulary classifies methylprednisolone for injection as green, suitable for routine use and can be prescribed within primary care within their licensed indication. Buckinghamshire CCG joint formulary states methylprednisolone should only be prescribed in secondary care by a specialist.

7.2	Since publication of the current policy, NICE has published Clinical Guideline 186 (2014, updated 2019) Multiple sclerosis in adults: management, which recommends that for treating a relapse and exacerbation, patients should be offered oral methylprednisolone 0.5 g daily for 5 days. IV 1g daily for 3–5 days should be considered as an alternative for people with MS in whom oral steroids have failed or have not been tolerated or who need admitting to hospital for a severe relapse or monitoring of medical or psychological conditions such as diabetes or depression.
7.3	An evidence search found one systematic review (SR) dated 2017 with an aim to compare the efficacy and safety of oral versus intravenous steroids for treatment of acute relapses in patients with MS. The review concluded that there were no clear-cut differences in the efficacy and overall tolerability between oral and IV steroids. Although this SR had some limitations to the studies within, the conclusions appeared to be in line with previously published RCTs, SRs and current national guidance.
7.4	The Committee was provided with cost information for oral methylprednisolone and IV methylprednisolone per course, excluding IV infusion costs. No identified individual funding request (IFR) activity was found across Thames Valley CCGs. CSU analysts were unable to identify IV administration of methylprednisolone however found some activity for elective patients with a primary diagnosis of MS and a code for continuous IV infusion of therapeutic substance when the commissioner was the CCGs rather than NHS England. This activity may relate to the administration of IV methylprednisolone.
7.5	The Committee considered the NICE guideline recommendations and evidence. It was agreed that the policy could be withdrawn as Thames Valley CCGs follow the current NICE guideline and will manage the prescribing of IV and oral methylprednisolone by appropriate classification in their CCGs' joint formularies. **ACTION: Clinical Effectiveness team to prepare CCG governing body papers recommending withdrawal policy recommendation statement 67: Intravenous versus oral steroids for exacerbations of multiple sclerosis**
8.	**Paper 20-008 – Policy Update: Chronic Fatigue Syndrome/Myalgic Encephalomyelitis**
8.1	East Berkshire, Berkshire West and Buckinghamshire CCGs have policies in place for chronic fatigue syndrome (CFS) dated from 2008. Oxfordshire CCG removed their CFS policy in 2014. These policies recommend the use of cognitive behavioural therapy (CBT) and graded exercise therapy (GET) for the condition stating that all other interventions and the provision of any intervention on an in-patient or residential basis is considered to be low priority due to lack of evidence of clinical and cost effectiveness.
8.2	The current position is based on NICE Clinical Guideline 53 (2007) Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy): diagnosis and management which recommends that CBT and/or graded GET should be offered to people with mild or moderate CFS/ME and provided to those who choose these approaches, because currently these are the interventions for which there is the clearest research evidence of benefit. Most people with CFS/ME will not need hospital admission. However, there may be circumstances when a planned admission should be considered. The decision to admit should be made with the person with CFS/ME and their family, and be based on an informed consideration of the benefits and disadvantages. New NICE guidance is currently in development with an anticipated publication date of April 2021. The scope for the new guidance indicates that since the 2007 guideline was published, the evidence for CBT and GET has been challenged.
8.3	The evidence review considered systematic reviews (SRs) and randomised control trials (RCTs) published since the SRs that examined CBT and/or GET as treatment for CFS. A 2019 Cochrane review comparing GET to other treatments concluded that GET probably has a positive effect on fatigue in adults with CFS compared to usual care or passive therapies, but that the evidence regarding adverse effects is uncertain. A 2020 SR including 18 studies concluded that although

8.3 Cont..	CBT and/or GET were a 'positive' treatment for CFS, the methodological quality of the studies was relatively low and potential bias was prominently detected. Further RCTs identified that were not included in the SRs did not provide robust evidence that CBT or GET were effective interventions for CFS. A 2013 SR that examined interventions for paediatric CFS was inconclusive. A 2012 RCT for an internet based CBT program for adolescents found CBT to be more effective than 'usual care'. The RCT, however, was open label and thus subject to bias, and only a limited description of 'usual care' was given by the authors.
8.4	The number of individual funding requests (IFRs) submitted over the last three years was low across Thames Valley: a total of 17, 14 of which were declined. Most of the requests were for out of area treatments although did not specify what treatment was requested. The Committee noted that the evidence review only considered CBT and GET, whereas the current policy states that all other interventions are considered low priority due to a lack of evidence of clinical and cost-effectiveness. The Committee agreed, however, that if there are other effective interventions for CFS available, the NICE guidance will be much more comprehensive. Additionally, as the number of IFR requests is low, there is no urgency to change the policy.
8.5	The Committee reviewed the evidence and agreed that due to the low numbers of funding requests and as NICE is publishing new guidance in April 2021, there would be no changes made to the policy at present. The Committee asked that the Clinical Effectiveness team programme the policy for further review following publication of the NICE guideline. **ACTION: Clinical Effectiveness team to update policy statement 76 and 130: Chronic fatigue syndrome/myalgic encephalomyelitis to note that they have been reviewed by the Committee adding a footnote to indicate that no changes had been made. The footnote should also note that the policy will be reviewed upon publication of new NICE guidance. The Clinical Effectiveness team to circulate for comment. Comments to be received within the 2 week period following issue.**
9.	**Any Other Business**
9.1	**Paper 20-009: TVPC63 Circumcision and Preputioplasty - clarification**
9.1	Concern has been expressed by an urologist from Oxford University Hospitals Foundation Trust. The following points were raised: ➢ In those children who have abnormal urine tracts anatomy, circumcision is a beneficial paediatric urology intervention with validity. Those with normal urinary tract anatomy do not need the operation. ➢ Similarly paraphimosis may result in a very damaged/scarred foreskin that ultimately requires circumcision (not the acute situation of paraphimosis It is suggested that the policy is amended to clarify that circumcision for pathological phimosis will be funded where clinically appropriate. Within the list of not normally funded indications, include: recurrent UTIs where there is no abnormal renal or urinary tract anatomy. **ACTION: The Clinical Effectiveness team to update TVPC63 Circumcision and Preputioplasty to clarify the position with regard to:** • **'Paraphimosis where the foreskin is retracted and cannot be returned back to the end of the penis' add (Circumcision for pathological phimosis will be funded). Post meeting note, sentence rephrased to state 'this does not include pathological phimosis'.** • **'Recurrent UTIs add 'where there is no abnormal renal or urinary tract anatomy'** • **A footnote to be added to highlight that where this is abnormal renal or urinary tract anatomy it is usually funded by NHS England Commissioning specialist urology service.** **As the updated policy is purely a clarification it was agrees that these changes do not require Governing Body acceptance.**

9.2	**TVPC Interim strategic lead**
9.2	The Clinical Effectiveness team highlighted that Louise Patten is no longer with her organisation. In the interim Robert Majiliton has agreed to take on the role of TVPC strategic lead.
9.3	**TVPC meeting arrangements going forward**
9.3	A discussion was held around the frequency and duration of future TVPC meetings **ACTION: Clinical Effectiveness team to send out new and revised TVPC calendar invitations for monthly meetings up to the end of November 2020.**
9.4	**Individual Funding Request**
9.4	The IFR team has received requests stating COVID-19 as a reason for exceptional circumstances. These have been declined on the basis that exceptional means exceptional from the vast majority of the population. COVID-19 has affected a significant portion of the population and therefore cannot be considered exceptional.
10.	**Next meeting**
	The next online meeting will be held on **Wednesday 22nd July 2020 from 2-3.30pm**
11.	**Meeting Close**
	The Chair thanked everyone for their contributions to the discussions and closed the meeting.