Northern, Eastern and Western Devon
Clinical Commissioning Group
South Devon and Torbay
Clinical Commissioning Group

Clinical Policy Engagement & Consultation Panel Meeting

Minutes

Wednesday 7 June 2017, 14.00-15.00

CFO Room, County Hall, Exeter and via teleconference

Present:

Ray Chalmers	Head of Communications & Strategic Engagement, South Devon & Torbay CCG
Rebecca Heayn	Clinical Effectiveness Governance Manager, NEW Devon CCG
Mac Merrett*	Lay Public Member, Clinical Policy Committee
Chris Peach*	Non-Executive Director (Patient & Public Involvement), South Devon & Torbay CCG
Chris Roome	Head of Clinical Effectiveness, NEW Devon CCG
Mark Taylor*	Lay Public Member, Clinical Policy Committee

* Denotes voting members

1. Welcome and Introductions

Attendees were welcomed to the meeting. Mark Taylor was welcomed to the panel as the new Lay Public Member of the Clinical Policy Committee.

Apologies were noted from Jenny McNeill, Associate, NEW Devon CCG and Jennie Willmott, Lay Member, Patient & Public Engagement, NEW Devon CCG.

It was noted that Jennie Willmott had shared her comments with the panel ahead of the meeting; these were considered during the meeting discussions.

2. Declaration of Interests

No specific interests pertinent to the items for discussion on the meeting agenda were declared.

Mac Merrett advised of a change to his declared interests; he is no longer a member of the Citizen Assembly. The Register of Interest would be updated accordingly.

3. Notes from the meeting 1 February 2017

The panel considered the notes from the meeting held on 1 February 2017 and agreed them to be an accurate record.

4. Discussion and recommendation on the Clinical Policy Committee decisions from 24 May 2017

Sodium oxybate for narcolepsy with cataplexy

A summary of the Clinical Policy Committee recommendation and considerations was noted by the panel. It was considered that it had been very helpful to have a specialist in attendance to address queries and enable a thorough debate of this policy area. It was felt that the committee had in the circumstances taken the pragmatic decision to recommend the use of sodium oxybate in Devon to ensure the continuation of the care of patients successfully treated as children under the NHS England policy criteria and, in the interests of ensuring equity, in adults who meet the same criteria.

The panel considered the public interest themes in relation to the proposed policy:

1. Is the reason for introducing the policy plausible? and 2. Does the policy output address this intent?

   It was noted that the reason for the Clinical Policy Committee re-consideration the CCGs' policy position in respect of sodium oxybate for the treatment of narcolepsy with cataplexy in adults (aged 19 years and over) was in light of the NHS England policy position for the treatment of children, which was published in December 2016. The NHS England policy describes the circumstances in which sodium oxybate will be available for the treatment of narcolepsy with cataplexy in children. There is no cure and most children treated under the policy are likely to require lifelong treatment. The commissioning responsibility for treatment passes to CCGs at the age of 19 years. However under the existing CCG policy position, patients who have been successfully treated under the NHS England policy would not be routinely eligible for continuation of their treatment at the age of 19.

3. Have the effects of the policy on individual patients and carers been considered?

   It was considered that the recommended policy will enable the continuation of successful treatment for those patients who may have been diagnosed and treated under the NHS England policy criteria as children, as they reach the age of 19. It will also ensure equity of treatment for those diagnosed as adults but meeting these same criteria. Sodium oxybate is a further treatment option which has been shown to offer an improvement in some of the major symptoms of narcolepsy with cataplexy. This may improve patients' quality of life and ability to undertake everyday activities, including maintaining employment or education, and reduce the risk of becoming socially isolated as it can be difficult to cope with emotionally.

4. Have the wider consequences on society been considered?

   It was felt that the wider consequences of the proposed policy had been considered. The pragmatic decision to change the existing policy position in respect of sodium oxybate would ensure equity of treatment of patients with narcolepsy with cataplexy at any age.

5. Has the opportunity cost been considered?

   The panel noted that the opportunity cost had not been well characterised by NHS England when they developed their policy as only the budget impact had been considered and no cost-effectiveness analysis had been conducted. The implications of this on local services was discussed and it was noted that the Clinical Policy Committee had identified that the CCG would face possibly insurmountable limitations to conducting a cost-effectiveness analysis. The panel noted that the number of patients expected to receive treatment, and therefore the amount of resources used would be small. The panel also noted that the proposed policy would achieve an unambiguous position that successful treatment would continue for children currently benefiting from sodium oxybate when they transition from NHS England commissioned services to CCG commissioned adult services. It was further observed that the proposed policy would achieve an equitable position for patients in the same clinical situation in adulthood. It was noted that the Clinical Policy Committee had asked the Chair to write to NHS England to highlight the issues raised during the discussion and the difficult position that the CCGs had been placed in as a consequence of the NHS England policy for the treatment of children.

6. Is there knowledge of public concern in relation to a) the disease and b) the specific intervention?

   The panel were not aware of any particular public concern regarding the condition or treatments for narcolepsy with cataplexy. It was commented that the patient numbers were small and noted that for rare conditions such as this, CCGs would not usually be the responsible commissioner, but this would be within the remit of specialised commissioning.

7. What information on the treatment and condition is available to patients via NHS Choices?

   NHS Choices includes information on treatments to manage the symptoms of narcolepsy and minimise the impact on patients' daily lives. This includes sodium oxybate, which it states can improve cataplexy and help patients sleep at night, also reducing daytime sleepiness. It notes that sodium oxybate is "not yet funded by the NHS in many areas"; however the NHS Choices information was last updated prior to the introduction of the NHS England policy.

Considering all these factors together the panel recommended that no further engagement or formal consultation was required at this point.

Lecicarbon A suppositories for constipation

A summary of the Clinical Policy Committee recommendation and considerations was noted by the panel. The Clinical Policy Committee had considered the use of lecicarbon A suppositories for the treatment of constipation following a consultant application. The applicant was in attendance at the meeting to contribute to discussions and it was commented that his presence clearly demonstrated the value of having specialist input into discussions.

The panel considered the public interest themes in relation to the proposed policy:

1. Is the reason for introducing the policy plausible? and 2. Does the policy output address this intent?

   It was noted that the proposed policy resulted from a consultant request to commission the treatment. The unanimous policy recommendation reached by the Clinical Policy Committee is to commission the routine use of lecicarbon A suppositories in Devon for the management of chronic constipation.

3. Have the effects of the policy on individual patients and carers been considered?

   It was discussed that this would represent an additional treatment option, considered as an alternative to phosphate enemas and/or rectal irrigation, in patients for whom conservative management and the use of other established laxatives were not effective. Lecicarbon A suppositories may of particular benefit to pregnant women or those who are breastfeeding as constipation is particularly common during pregnancy, but neither lubiprostone nor prucalopride are recommended for use in pregnancy.

4. Have the wider consequences on society been considered?

   It was felt that there were no wider consequences of the proposed policy; this represents an additional treatment option for patients with chronic constipation where conservative management and other established laxatives were not effective.

5. Has the opportunity cost been considered?

   Although it had not been possible to quantify the overall budget impact, it was noted lecicarbon A suppositories are considered to offer value for money. They are cost saving compared with phosphate enemas and offer an additional treatment option prior to the use of lubiprostone or prucalopride, both of which are significantly more expensive.

6. Is there knowledge of public concern in relation to a) the disease and b) the specific intervention?

   It was discussed that constipation was fairly common, but there the panel were not aware of any public concern regarding the condition or specific treatment options.

7. What information on the treatment and condition is available to patients via NHS Choices?

   Lecicarbon A suppositories are not specifically listed on NHS Choices, however there is a general section giving information on the various treatment options available for constipation depending on the cause, duration and severity of symptoms. This includes lifestyle advice, laxatives and rectal treatments (which include suppositories and mini-enemas).

Considering all these factors together the panel recommended that no further engagement or formal consultation was required at this point.

5. Annual Report 2016-17

Rebecca Heayn presented an overview of the Clinical Policy Engagement and Consultation Panel Annual Report 2016-17. The first annual report of the panel had explained the development and subsequent operation of process; this second annual report reflected a year of functioning and refinement of an established process.

Five meetings were convened in 2016-17, considering and making recommendations to the CCGs on a total of 15 clinical policy recommendations. On discussion of these recommendations, the panel had been satisfied that the public interest issues had been fully considered and that further engagement or formal public consultation activity would not yield additional insights.

However the panel formally documented their views and made some additional recommendations for action arising from the consideration of specific policies. This included seeking further intelligence and data to establish a baseline position prior to the publication of certain policies to be able to understand the impact of these, to understand the uptake of the Clinical Policy Patient Support Information that had been produced, and discussions relating to statements of functional limitation needing to be contextualised by the procedure or condition under review.

Following presentation of the previous year's Annual Report to the CCGs, the clinical policy communication process has been strengthened to ensure that community representatives routinely received details of the publication of new or updated policies, in conjunction with the communication and engagement team.

One of the most significant additions to the process has been routine consideration of the information available to patients via NHS Choices in respect of the treatment and condition under review. It was felt that this is often the first point of reference for patients, and therefore an awareness of the NHS public information available, and hence patient expectations, was a useful addition to considering the patient interest issues. This has in turn had an impact on the process of the Clinical Effectiveness team, with this being a routine consideration when looking at drugs and treatments for particular conditions.

Clear governance arrangements are in place in respect of declaration of interests and onward reporting. A register of interests, terms of reference, minutes and meetings arrangements are all made publicly accessible online. The annual report will similarly be made available once accepted by the CCGs.

Following discussion with those present and taking into consideration comments received ahead of the meeting, an amendment was agreed in respect of 2.6 to clarify the remit of the Governing Body Lay Members. This would be altered to read "Governing Body Lay Members who champion patient and public involvement".

It was also agreed that it may be helpful to include some further detail about how the policy areas considered by the panel are identified in the first instance for consideration by the Clinical Policy Committee. It was suggested that a section from the Clinical Policy Committee Annual Report detailing the sources contributing to the work programme, and a diagram showing the Committee input and outputs, be added to give some broader context. This would ensure

consistency across the Annual Reports and also enable them to be read as standalone documents.

It was agreed that the changes to the Annual Report would be made as discussed and this would be re-circulated to the panel members. The Annual Report will then be submitted to the respective CCGs for information and assurance.

6. Any Other Business

The panel briefly discussed the emergence of a new South Devon and Torbay Joint Clinical Effectiveness Group (between the CCG and the acute trust) which appeared to have commissioning policies as one of its outputs. Chris Peach had limited knowledge of the group and did not know that policy was an intended output. The panel felt it was not clear where this sat in relation to the processes agreed between the two CCGs for policy recommendation and the processes for consideration of the public interest issues before policy ratification. In addition to a general query about the processes that had been approved, the panel also felt that there was potential for policies that originate through different streams to conflict with each other. The panel asked if the Terms of Reference of this new group could be made available to them.

7. Date of next meeting

The panel was asked to consider rearranging the next meeting which had been scheduled for Tuesday 8 August. This would accommodate the preparation of the meeting papers during the traditionally busy holiday period following the next Clinical Policy Committee meeting.

As a result, the next meeting is now due to be held on Thursday 18 August 2017 from 2.00pm in the CFO Room, County Hall, Exeter or via teleconference.

ACTION LOG

Action no.	Meeting date	Action description	Lead(s)
17/01	09/06/2017	Rebecca Heayn to make changes to the Annual Report as discussed and re-circulate to the panel members.	Rebecca Heayn
17/02	09/06/2017	Annual Report to be submitted to the respective CCGs for information and assurance.	Rebecca Heayn
17/03	09/06/2017	Chris Roome to request South Devon and Torbay Joint Clinical Effectiveness Group Terms of Reference and overview of approval processes.	Chris Roome