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

Clinical Policy Engagement & Consultation Panel Meeting

Minutes

Wednesday 11 October 2017, 14.00-15.30

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
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
Jennie Willmott*	Lay Member, Patient & Public Engagement, NEW Devon CCG

* Denotes voting members

1. Welcome and Introductions

Attendees were welcomed to the meeting.

Apologies were noted from Jenny McNeill, Associate, NEW Devon CCG and Mac Merrett, Lay Public Member, Clinical Policy Committee.

2. Declaration of Interests

No changes to the Register of Interest were advised and no specific interests pertinent to the items for discussion on the meeting agenda were declared.

3. Notes from the meeting 17 August 2017

The panel considered the notes from the meeting held on 17 August 2017 and agreed them to be an accurate record.

The action log was updated as follows:

Action no.	Description and update
17/02	Annual Report to be submitted to the respective CCGs for information and assurance. **The Annual Report was received by the first NEW Devon CCG and South Devon and Torbay CCG Engagement Committee in common on 5 October. Action complete.**

17/04	Meeting dates for 2018 to be arranged and circulated for advanced diary planning. **Rebecca Heayn had circulated provisional meeting dates for 2018 to the panel members. Action complete.**

4. Discussion and recommendation on the Clinical Policy Committee decisions from 27 September 2017

Cryopreservation to preserve fertility policy

A summary of the Clinical Policy Committee recommendation and considerations was noted by the panel. The revised CCGs' cryopreservation to preserve fertility policy proposes that cryopreservation will be routinely funded for patients aged 39 years and younger who meet the criteria; includes the long term use of gonadotoxic drugs; and is funded for patients in whom stopping treatment for a prolonged period of time to enable conception is not an option. It is now clarified that sterilisation includes individuals in whom sterilisation has been reversed, and that cryopreservation will not be funded solely because individuals wish to delay conception, e.g. for personal lifestyle reasons. There continues to be an initial storage period of five years, with renewal of storage now at five year intervals up to the 40th birthday following discussion between the clinician and patient.

Local fertility specialists were present at the Clinical Policy Committee meeting and had been actively engaged in the process for revising the policy.

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 revision of the current policy had arisen in response to a number of requests for clarification on certain policy areas through the experiences of the Individual Funding Request Panel and local clinical specialists. Revision of the policy, including reformatting for clarity, has therefore been undertaken following consultation with local fertility specialists.

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

   It was discussed that a significant proportion of cryopreserved material is not used. This may reflect the health and personal circumstances of affected individuals, and also that the decision to opt for cryopreservation needs to be taken promptly within the context of a diagnosis and other treatment considerations. There are currently no age limits and no differences in the length of time for which the NHS will fund storage for individuals. It was clarified that this policy is distinct from the CCGs' policy for Assisted Conception and the criteria for infertility investigation and treatment; eligibility for cryopreservation is not affected by whether an individual already has children.

   The revised policy proposes that cryopreservation will be routinely funded by the NHS for eligible patients aged 39 years and younger. There continues to be an initial storage of five years, but renewal will now be at five year intervals up to the 40th birthday, rather than a cap of ten years for all patients.

   It was noted that local specialists felt that this was a big step forward for younger patients, who are more likely to use their cryopreserved material, targeting resources to those who have not had the opportunity to have a family by extending the time for which their samples can be stored beyond ten years.

   However it was discussed that the introduction of an age limit will affect some individuals who will now no longer receive NHS funded cryopreservation, either as new patients or for continued NHS funded storage. The panel queried why the particular age limit had been chosen, and why this applied to both sperm and eggs. It was explained that this had been based on the age at which mothers and fathers in the general population first have children,

with reference to Office for National Statistics data. This showed that 95% of births occurred in mothers aged 39 years and younger and 85% in fathers of the same age. It had also been proposed that there should be equity between men and women in the age of patients who meet criteria for NHS funding. It was discussed that for individuals over 40 for whom NHS funding would cease, conversations with their fertility specialist would include the choice of whether to self-fund continued storage. Individual Funding Request Panel processes are also in place for individuals to be considered for exceptional funding for cryopreservation outside of the policy criteria.

4. Have the wider consequences on society been considered?

   It was felt that there were no wider consequences of the proposed policy; this is an area with no broader impact beyond the individuals involved.

5. Has the opportunity cost been considered?

   It was noted that it had not been possible to establish accurate estimates of the cost implications of the proposed policy changes; some patients will no longer be eligible for initial or continuation of storage, and others will be eligible for longer storage. On balance, the budget impact was not thought to be great. However the intention was to target NHS funding resources to those who would be most likely to benefit.

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

   It was noted that matters relating to fertility are a sensitive topic and are a common area of enquiry to the CCGs. As this is an area delegated for local commissioning decisions to be taken, there is variation in the provision and criteria specified in policies across the country.

   The panel discussed the merits of conducting further engagement or consultation on this policy area, what the focus of this would be, and whether it would be helpful or meaningful. In this particular case the panel noted that the numbers of patients affected were low, but there was a patient group receiving an ongoing service for which NHS funding would cease at a defined future date depending on their current age. For some this will be entitlement to NHS funding for a longer storage period whilst for others this would now cease sooner than they may have expected.

   It was therefore suggested that patients who currently have cryopreserved material should be informed of the revisions to the policy so that they can understand how this may affect them. The CCGs should engage with the fertility centres in order to identify and communicate with those individuals affected.

   In the event of significant concern raised by patients affected, it was agreed that the Clinical Policy Committee should be informed and asked to reconsider the policy position.

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

   NHS Choices includes information on medicines and drugs that can affect an individual's fertility; it also includes specific advice on cancer and fertility issues. This advises women to discuss the options for preserving their fertility with their doctor before starting cancer treatment, and if it is felt that there is enough time before starting treatment, they could be referred to a fertility clinic. Possibilities include storing frozen embryos (fertilised eggs), freezing unfertilised eggs and storing them, and freezing and storing ovarian tissue. However the storage of ovarian tissue and its use in fertility treatments is still fairly new.

   Men are advised that it may be possible to store some of their sperm before they start treatment (sperm banking) to be frozen and stored for use in the future as part of fertility treatment. However under some circumstances, their doctor may not want to delay starting their cancer treatment. It is advised that sperm banking is available on the NHS, but that in some circumstances there may be a need to go private.

The panel noted that there would be a patient group receiving an ongoing service for which NHS funding would cease at a defined future date depending on their current age. For some this will be entitlement to NHS funding for a longer storage period whilst for others this would now cease sooner than they may have expected.

After considering all the patient interest factors the panel recommends that patients who currently have cryopreserved material are informed of the revisions to the policy so that they can understand how this may affect them.

Further, the panel recommends that in the event of significant concern raised by patients affected, the Clinical Policy Committee should be informed and asked to reconsider the policy position.

Proposed changes to the commissioning policy for Assisted Conception

A summary of the Clinical Policy Committee recommendation and considerations was noted by the panel. The Clinical Policy Committee had considered four amendments to the Assisted Conception policy to provide clarification in certain areas and to reflect changes in commissioning responsibility in others. It was explained that certain statements on surgical sperm retrieval are to be deleted from the policy as NHS England has taken over commissioning responsibility for these procedures. It is also proposed that the text in the policy is amended to leave reference to the existence of a separate policy for cryopreservation to preserve fertility but not to replicate details of this. This will enable the respective policies to be updated independently.

The focus of discussions had related to donor insemination for clinical indications (i.e. where the male partner is likely to pass on an inheritable genetic condition, an infection such as HIV etc.) and whether the use of nicotine replacement therapies (NRT) or e-cigarettes should affect eligibility for assisted reproduction techniques.

Local fertility specialists were present at the Clinical Policy Committee meeting and had been actively engaged in the process for revising the policy.

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

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

   It was noted that fertility specialists had asked for clarification within the policy of the method of conception which the CCGs will routinely fund for donor insemination for clinical indications.

   With the increase in the use of e-cigarettes as a means of smoking cessation, enquiries from fertility centres had also prompted the need for clarification as whether the criterion for smoking also applies to e-cigarettes and NRT.

3. <u>Have the effects of the policy on individual patients and carers been considered?</u>

   It was noted that the proposed changes to the policy enable patients for whom donor sperm is required for a clinical indication to choose between either one cycle of IVF, unstimulated intrauterine insemination (IUI) (up to six cycles) followed by one cycle of IVF if IUI is unsuccessful, or three cycles of stimulated IUI followed by one cycle of IVF if IUI is unsuccessful. Although local specialists considered unstimulated IUI to be less efficient than stimulated IUI, it was acknowledged that there were relative benefits of each option based on individual patient circumstances and preferences, for example with regard to the level of intervention and drugs used as part of the treatment.

   It was considered that the proposed policy addition in respect of the use of NRT or e-cigarettes did not represent a change, but brought clarity to a previously grey area. It would now explicitly confirm that there is insufficient evidence currently to exclude patients who use NRT or e-cigarettes from NHS treatment.

4. Have the wider consequences on society been considered?

   It was felt that there were no wider consequences of the proposed policy; this is an area with no broader impact beyond the individuals involved.

5. Has the opportunity cost been considered?

   It was noted that the proposed changes to the policy are not expected to increase the number of patients referred for investigation or treatment.

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

   The panel acknowledged that matters relating to fertility are a sensitive and contentious topic and are a common area of enquiry to the CCGs. However it was felt that this was more specifically focused on the provision of IVF, to which no change is proposed, rather than the provision of IUI.

   It was commented that the policy wording relating to smoking reinforces the message that society is troubled by smoking and its negative effects. The explicit statement that patients who use NRT or e-cigarettes would not be excluded from NHS treatment supports this message and encourages people to quit smoking. If evidence subsequently comes to light which suggests that NRT or e-cigarettes have a negative effect on the outcome of assisted reproduction techniques, the CCGs' position could be reconsidered at this time.

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

   NHS Choices gives information on the treatment of infertility. This clarifies that fertility treatment funded by the NHS and eligibility criteria varies across the UK.

   Information is given on IUI. This states the circumstances under which IUI may be offered, but that the eligibility criteria may vary and patients should find out what the rules are where they live from their GP or local CCG. It is explained that IUI may be offered in a natural (unstimulated) cycle or in a stimulated cycle.

   NHS Choices states that smoking (including passive smoking) affects a woman's chance of conceiving, and in men there's an association between smoking and reduced semen quality. However no specific mention is made of the effects of e-cigarettes or NRT on fertility and eligibility for infertility investigation or treatment.

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

5. Any Other Business

No other business was raised by the panel members.

6. Date of next meeting

Future meeting dates

The next meeting is due to be held on Tuesday 12 December 2017 from 2.00pm in the CFO Room, County Hall, Exeter or via teleconference.

ACTION LOG

Action no.	Meeting date	Action description	Lead(s)
17/05	11/10/2017	Letter to be drafted to inform patients who currently have cryopreserved material of the revisions to the policy so that they can understand how this may affect them. The CCGs should engage with the fertility centres in order to identify and communicate with those individuals affected. This should to accompany communication/publication of the revised cryopreservation to preserve fertility policy (subject to approval by the CCGs).	Chris Roome