Clinical Policy Engagement & Consultation Panel Minutes

Thursday 18 July 2024, 14.00-15.00
G05, Aperture House, Exeter and via Microsoft Teams

Present:

Name	Role
Thandiwe Hara*	Non-executive director for citizen and community involvement, NHS Devon
Carol McCormack-Hole*	Lay Member from the Patient Engagement Forum
Mac Merrett*	Lay Public Member, Clinical Policy Recommendation Committee
Martyn Nicoll	Patient Experience Manager, NHS Devon
Rebecca Owen	Clinical Effectiveness Governance Manager, NHS Devon
Chris Roome	Head of Clinical Effectiveness, NHS Devon
Mark Taylor*	Lay Public Member, Clinical Policy Recommendation Committee

* Denotes voting members

1. Welcome and introductions

The group were welcomed, and apologies noted.

Apologies:

Name	Role
Nicola Bonas	Associate director of communications, involvement and inclusion, NHS Devon

2. Declarations of Interests

All those attending had previously completed a declaration of interests which has been recorded on the panel's register of interests.

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

3. Minutes of the meeting held on Thursday 9 May 2024 and matters/ actions arising

The panel considered the minutes from the meeting held on Thursday 9 May 2024 and agreed them to be an accurate record. The action log was updated as follows:

Summary of actions			
	Action	**Lead(s)**	**Status**
23/02	Share the panel's discussion and question regarding cost recovery from the private sector with the finance team.	Chris Roome	Chris Roome previously reported that he had raised this query with the finance team and been advised that there is no mechanism for recovery of costs from private sector providers where the NHS had to step in and provide a subsequent procedure. The panel expressed their surprise at the lack of mechanism and asked whether this issue could be escalated, via the finance team, to a national forum. They remain concerned at the potential for this to be growing area and a recurring concern, which will be applicable beyond breast implant removal to other procedures, and an increasing burden on the NHS. Update: Chris Roome confirmed that the panel's concern has been highlighted to the Deputy Director of Finance. Action closed.
24/01	Annual Report to be reported onwards in the ICB for information and assurance	Rebecca Owen	This was received by the Clinical Policy Recommendation Committee at their meeting on 26 June and will now be reported onwards in the organisation for assurance. Action closed.
24/02	Contact panel members to confirm availability for rescheduling the September meeting	Rebecca Owen	The meeting has been rescheduled for Thursday 3 October. Action closed.

4. Discussion and recommendation on the Clinical Policy Recommendation Committee (CPRC) decisions from 26 June 2024

Continuous glucose monitoring (CGM) in diabetes

An overview of the Clinical Policy Recommendation Committee recommendation and the context within which it had arisen was noted by the panel.

Continuous glucose monitors (CGM) are used by some patients with diabetes to measure their glucose levels. They are small wearable devices which allow users to take measurements of their glucose by sampling interstitial fluid found directly under the skin, either intermittently scanned (requiring users to actively take readings) or real time (continually taking readings and passing the information to a reader device).

NHS Devon has an existing policy in place, developed in line with National Institute for Health and Care Excellence (NICE) guidance, which commissions real time CGM for all patients with type 1 diabetes and intermittently scanned CGM in a small, specified group of adult patients with type 2 diabetes. NICE published an update to guideline NG18 on Diabetes (type 1 and type 2) in children and young people in May 2023 which includes a new recommendation in respect of the provision of real time CGM to children and young people with type 2 diabetes.

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

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

   It was noted that review of NHS Devon's existing policy for CGM had been prompted by the update to NICE guideline NG18. NG18 includes a new recommendation that real time CGM should be offered to children and young people with type 2 diabetes when they have a need, condition, or disability that means they cannot self-monitor their own blood glucose, or they would otherwise need to self-monitor blood glucose 8 or more times daily, or they have recurrent or severe hypoglycaemia. It is also recommended that real time CGM should be considered for children and young people with type 2 diabetes who are treated with insulin. This group is not currently included within the existing NHS Devon policy.

   The Clinical Policy Recommendation Committee has subsequently recommended an update to the policy to include the routine commissioning of CGM in children and young people with type 2 diabetes.

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

   It was noted that this change to the policy would be beneficial for the patient group concerned, who it was highlighted are often living with other health conditions such as learning disabilities, autism spectrum disorder, or mental health issues. Extension of CGM provision to include them would help support a reduction in health inequalities and improvement of health outcomes.

   The panel queried at what age these devices would be used, and it was noted that devices are not licensed for use below the age of 2 years. Type 2 diabetes is unusual in children of any age and most cases would be expected to be diagnosed in later childhood. It would be exceptionally unusual to diagnose type 2 diabetes in children too young to use an approved CGM device.

4. **Have the wider consequences on society been considered?**

   It was acknowledged that NHS Devon has a statutory duty under the Health and Social Care Act (2022) to reduce health inequalities with respect to the outcomes achieved for the population of Devon due to the provision of health services. It also

has a strategic goal of reducing health inequalities especially those experienced by individuals living with mental illness, learning disabilities, and/or autism.

5. **Has the opportunity cost been considered?**

   It was discussed that the update to the policy is expected to apply to only a small number of patients as type 2 diabetes is not common in children and young people.

   Data from the national paediatric diabetes audit identifies the likely number of children and young people living with type 2 diabetes in Devon to be 13, although it was noted that some of these individuals may already qualify for CGM under the existing policy criteria.

   In terms of budget impact, the clinical effectiveness team assessed that the current costs for finger prick blood testing for glucose monitoring can be offset against the increased costs of CGM use. Taking this into account, the additional cost for extension of provision to this patient group was estimated to be around £8,012 based on patients receiving GP prescribable CGM devices.

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 relating to this patient group, although it was acknowledged that they may experience health inequalities.

   The provision of real time and intermittently scanned CGM for patients in Devon has previously been a prominent issue and one for which a significant number of contacts and queries had been received by the ICB.

7. **What information on the treatment and condition is available to patients via nhs.uk (formerly NHS Choices)?**

   nhs.uk gives information on continuous glucose monitoring (CGM) and flash; however this specifically relates to individuals with type 1 diabetes.

   It is stated that CGM or flash glucose monitoring should be available on the NHS to anyone with type 1 diabetes. Children and young people will usually be offered CGM. Adults will usually be offered a choice of CGM or flash.

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

Guanfacine for attention deficit hyperactivity disorder (ADHD) in adults

An overview of the Clinical Policy Recommendation Committee recommendation and the context within which it had arisen was noted by the panel.

ADHD is a neurodevelopmental disorder primarily diagnosed in children and adolescents. The diagnosis often continues into adulthood, with some patients requiring continued treatment. Management in both children and adults involves a combination of non-pharmacological therapy-based interventions and drug treatment.

Guanfacine is a drug treatment licensed for the treatment of ADHD in people aged 6 to 17 years of age. NHS Devon has an existing commissioning policy which supports its use for the management of ADHD in children and adolescents under certain criteria, however there is currently no commissioning policy for its use in adults. This has resulted in queries relating to the management of patients initiated on guanfacine as children who later transition to adult services, in addition to adults who have not previously been treated with guanfacine.

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

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

   It was noted that NHS Devon has an existing policy for the use of guanfacine for the management of ADHD in children and adolescents, however there is no commissioning position for its use adults. This has resulted in queries from clinicians seeking clarity on whether treatment can be continued into adulthood for patients initiated on guanfacine as children, as well as the initiation of treatment with guanfacine in adult patients.

   Following consideration, the Clinical Policy Recommendation Committee has recommended a commissioning policy which does not support the use of guanfacine in Devon for the treatment of ADHD in adults. Guanfacine is not licensed for adults with ADHD and the evidence for its efficacy in adults is extremely limited.

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

   There was discussion of the impact on patients taking guanfacine transitioning from children's to adults' services from the expectation to withdraw treatment.

   It was acknowledged that changes of medication can be tricky for clinicians but that it was appropriate to re-challenge the tolerability of treatments when patients become adults. There is low use of guanfacine in children and it is suggested that the number of patients requiring guanfacine once they reach adulthood is likely to be low as they are often able to tolerate licensed treatments they could not when they were younger.

   However clinical discussion needs to occur with the patient to support appropriate review. Ideally patients approaching transition between services would be known about in advance to enable this to be planned. It was recognised that this can be challenging in practice, and therefore a form of words would be included in the Devon Formulary to support the timescales for managing the review of drug treatment for patients transitioning to adult services.

   The panel considered the level of risk to patients and families, noting that this was felt to be low risk in terms of the side effect profile of the drug, and also in terms of the associated behaviour changes for patients with ADHD.

   Adult patients with exceptional clinical circumstances who require guanfacine may be able to access the drug via the Individual Funding Request Panel process.

4. **Have the wider consequences on society been considered?**

   It was felt that there were no wider consequences of the proposed policy beyond the individuals involved.

5. **Has the opportunity cost been considered?**

   It was noted that average treatment costs for guanfacine are higher than currently available, licensed options. Adult patients with exceptional circumstances who require guanfacine may be able to access the drug via the Individual Funding Request Panel process.

   It was queried whether there is likely to be an increase in the prescribing of guanfacine in future for children with ADHD, and if so, the associated impact of this on the transition to adult services. It was discussed that the levels of use of guanfacine in Devon can be monitored through prescribing data, and any future changes in the evidence base for guanfacine could prompt review of the NHS Devon policy positions.

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 in respect of ADHD or the specific use of guanfacine. There are a range of existing licensed drug treatment options for use in adults with ADHD.

7. **What information on the treatment and condition is available to patients via nhs.uk (formerly NHS Choices)?**

   nhs.uk gives information on treatment for ADHD to help relieve the symptoms and make the condition much less of a problem in day-to-day life.

   It is stated that there are five types of medicine licensed for the treatment of ADHD; methylphenidate, lisdexamfetamine, dexamfetamine, atomoxetine and guanfacine.

   Guanfacine acts on part of the brain to improve attention, and it also reduces blood pressure. It is usually taken as a tablet once a day, in the morning or evening. Guanfacine may be offered to teenagers and children over the age of 5 years if it is not possible to use methylphenidate or lisdexamfetamine. It is not recommended for treating adults with ADHD without specialist advice.

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

Myringotomy (with or without grommet insertion) and adjuvant adenoidectomy in children under 12 years with otitis media with effusion (OME)

An overview of the Clinical Policy Recommendation Committee recommendation and the context within which it had arisen was noted by the panel.

Otitis media with effusion (OME), also referred to as glue ear, is a common childhood condition characterised by a build-up of fluid in the middle ear which, for some children, can affect their hearing. In most cases, the condition responds spontaneously within a few weeks but persistent cases with a sustained effect on hearing can cause language, educational, and behavioural problems. Treatment is only indicated were it is associated with hearing loss. Options include hearing aids and surgical management (myringotomy, grommet insertion, and adjuvant adenoidectomy).

NHS Devon has an existing policy in place for myringotomy/grommet insertion and adjuvant adenoidectomy for glue ear in children under 12 years which reflects NICE guideline CG60. NICE published an updated guideline on otitis media with effusion in under 12s (NG233) in August 2023 in which recommendations on the use of surgery for glue ear are less restrictive.

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

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

   It was noted that review of NHS Devon's existing policy for myringotomy/grommet insertion and adjuvant adenoidectomy for glue ear in children under 12 years had been prompted by the publication of NICE guideline NG233 on otitis media with effusion in under 12s. NG233 recommends treatment is considered for those with persistent hearing loss greater than 20 decibels, surgery for unilateral OME where hearing difficulties impact on daily living or communication, and adjuvant adenoidectomy for all children undergoing grommet insertion.

   Following consideration the Clinical Policy Recommendation Committee has recommended an updated policy which supports surgery for unilateral OME, reduces the hearing level threshold for treatment in bilateral OME to cover all degrees of hearing loss, and also includes revision of the wording around watchful waiting periods, following specialist feedback, to reduce ambiguity. No changes are however proposed to the existing commissioning criteria for adenoidectomy.

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

   It was considered that the proposed changes to the policy criteria to lower the hearing level thresholds for treatment and to enable surgery to be undertaken for unilateral as well as bilateral glue ear will be beneficial for some patients and their parents/carers. This will enable treatment for all children with minor glue ear related hearing loss, and for children with persistent unilateral glue ear with hearing loss that significantly impacts their developmental, social, or educational status.

   The panel discussed the proposal to make no change to the policy criteria for adenoidectomy, noting that local specialists support undertaking adenoidectomy in line with the current criteria, i.e. on recurrence rather than routinely in all patients. Specialists also feel this supports best use of their surgical capacity as undertaking adenoidectomy is associated with a longer procedure time.

   It was discussed that there are long waiting times at present for grommet insertion and in the interim patients are being offered hearing aids. This is not the situation that NICE had anticipated; they expected that patients would be offered either

hearing aids or surgery. The economic impact of patients effectively receiving two treatments due to long waiting times means that there is a reluctance to place further pressure on local surgical capacity, and to further increase waiting times for patients.

It was clarified that the same surgeons would undertake both procedures, although glue ear is much more common than adenoidal problems. If a patient had an adenoidal problem this would still be treated separately.

4. **Have the wider consequences on society been considered?**

It was felt that there were no wider consequences of the proposed policy beyond the individuals involved and their parents/carers.

5. **Has the opportunity cost been considered?**

It was noted the proposed change to hearing level thresholds is not expected to affect local activity levels. However commissioning surgery for unilateral glue ear is expected to result in an increase in grommet insertion procedures to an additional 42 procedures per year within Devon, with an associated increase in cost of approximately £40,000.

It is not proposed to widen the existing criteria for adenoidectomy. During consultation with local specialists it was identified that there are already long waiting times for grommet insertion in Devon and extending adenoidectomy provision would lead to increased costs and impact surgical capacity further with longer procedure times. They support the continued use of adenoidectomy in line with the existing policy criteria.

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 in respect of glue ear and its treatment options.

7. **What information on the treatment and condition is available to patients via nhs.uk (formerly NHS Choices)?**

nhs.uk states that glue ear is where the middle part of the ear canal fills up with fluid. The most common symptom of glue ear is temporary hearing loss. It can affect both ears at the same time. If glue ear lasts a long time, it can affect a child's speech development and progress at school. Glue ear is much more common in children, but adults with glue ear have the same symptoms.

Glue ear is not always treated. The GP will usually wait to see if the symptoms get better on their own. This is because there is no effective medicine for glue ear, and it often clears up on its own within 3 months. Your child may be monitored for up to a year in case their symptoms change or get worse.

Your child may be referred to a specialist in hospital if glue ear symptoms are affecting their learning and development, they already had severe hearing loss

before glue ear, or they have Down's syndrome or a cleft lip and palate, as glue ear is less likely to get better by itself.

The two main treatments are temporary hearing aids or grommets (small tubes implanted in the ear). Occasionally, surgery may be recommended to remove some glands at the back of the nose (adenoids). This is known as an adenoidectomy.

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.

6. Next meeting date

The next panel meeting will be held on **Thursday 3 October 2024**.

In addition to having been circulated via email, it was noted that the dates of future meetings were included on the agenda for panel reference.