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Mindworks Surrey

The children and young people's emotional wellbeing and mental health service

NHS
Surrey and Borders Partnership
NHS Foundation Trust

Mindworks Surrey – ADHD LCS summary

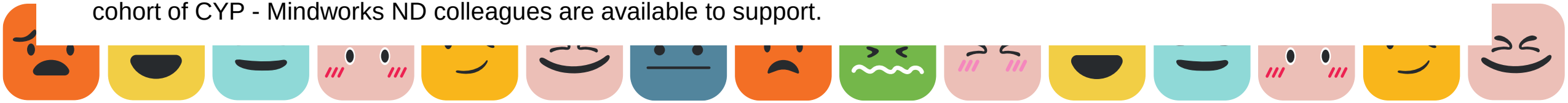
November 2024

Locally Commissioned Service : Attention Deficit Hyperactivity Disorder (ADHD) in children and young people aged 6-17 years old

- As part of the review of Locally Commissioned Services (LCSs), there are changes to the ADHD LCS, which have now been shared, with sign up by January 2025.
- Ahead of that, we wanted to give an update on the context and purpose of the LCS, explains what's included (and what's changed) and gain your support in helping build engagement with our primary care colleagues.

Background - partnership approach across One System Mental Health Plan, All-Age Autism Strategy and Additional Needs and Disabilities Partnership

- **As part of the work to support improvements for CYP with neurodiversity, we've been seeking feedback** from CYP, their families and wider partners
- **We've heard support for moving away from a diagnostic focused approach to an approach where CYP are identified and supported much earlier**, through strategies and other interventions. This will evolve with 3 / 4 Place ND Community of Practice Events.
- **We also heard feedback in relation to the ongoing management of children and young people with ADHD** – we've worked with primary care colleagues to revise this LCS which offers the safe transfer of care for non-complex, stable CYP into primary care, with open access to advice and guidance or referrals back into more specialist services, where needed.
- **Key that all partners are equipped to help families,** by utilising system partnerships to support the needs of this increasing cohort of CYP - Mindworks ND colleagues are available to support.



Understanding the LCS within the context of supporting CYP with neurodiversity

Quote from a parent that reached the ICB through long processes and complaint procedures.

‘I really want to understand my child’s needs and how my child’s needs can be supported. I want my family to believe my child is autistic and will get off my back and help, waiting for a diagnosis is the only answer, I’m tired of fighting the system’

Transformation Map

Data / Insight and Commissioning will be a thread throughout the map ensuring data compliance, accountability and assurance and service improvement

What is our overall purpose?

For Surrey CYP who are neurodiverse and/or referred to the ND Pathway are thriving and feel a sense of belonging

What key objectives will achieve our purpose?

EARLY SUPPORT: CYP & FAMILY SUPPORT	EARLY SUPPORT THROUGH SCHOOLS AND COMMUNITY	TIMELY ACCESS TO DIAGNOSIS	CRISIS SUPPORT	COMMUNICATION & ENGAGEMENT	WORKFORCE
Provision of accessible CYP and parenting information, advice and support	Provide capacity and learning opportunities to increase schools' response within ordinarily available provision (OAP).	Seamless service delivery across all age groups NHS and right to choose.	Provide integrated service in line with recommendations from the Urgent Emergency Care review.	Ensure voices of CYP, families, stakeholders and partners are heard	Explore an alternative workforce and skill mix to deliver the ND Pathway

What do our services need to deliver?

Effective communication. Effective strategies. Rolling program of CYP and parenting programs.	Whole school assessment and response plans, training, role modelling and learning together. Profiling tool competency.	Mindworks Transformation Plan. Clear pathway with Epsom and under 6s'. LCS with primary care.	Joined up integrated, child centered approach - health and social care	Clear opportunities for CYP and stakeholders to be involved in ND pathway improvement.	Providers / partners need to tell us their current workforce issues via the ND Workforce Survey.

What do we need to be really good at?

Identify needs and match the response to support needs so families experience change.	Understanding the driver for demand to improve support.	Delivering clearly defined diagnostic services with accessible pathway details clearly shared.	Delivering trusted assessor models of care with flexible support that can reach into homes as well as acutes / social care/ disabilities services/ MH	Engaging and involving CYP, families and stakeholders in co-design and research	Exploring the possibilities of alternative workforce and integration

How will we know we are performing well?

CYP and families experience early support and difficulties identified being reduced	CYP and Families reporting improved understand of Thrive continuum	Early support available & evidencing improved outcomes	Increasing number of schools that identify themselves as ND friendly.	Complex diagnostic Needs of CYP met by Mindworks.	Accessible Right to Choose services meeting ASC + ADHD needs	More CYP have ADHD medication reviews managed by primary care and transitions are smooth	CYP in crisis receive support builds keeping them at home.	Informed and influencing CYP, Families and Wider partners	CYP, Families, Schools and Partners delivering service reporting improved connections and understanding	Confident, competent workforce with skill mixed / increased integrated approach

What are the core elements of this LCS for children?

- Transfer of care for treatment of children and young people with ADHD in cohort 1 who have been identified by SABP as ‘fully stable’
- Shared Care of agreed stable patients with 12 monthly monitoring by primary care (cohort 2) with ADHD in CYP aged 6-17 years old.
- Practices would deliver both elements of the service (i.e. support CYP in cohort 1 and 2).
- This is available for individual practices or as a collaboration with PCN or sub-contracted to Federation

Cohort	Summary	Changes introduced as part of this LCS
Cohort 1 – Children and young people with ADHD who are stable, where **care can be transferred to primary care**	Stable is defined as: • Fully stabilised dose (i.e. titrated dose of medication which has not been changed in the last 6 months) • uncomplicated by co-morbidities (i.e. currently not receiving specialist treatment for other mental health or neurodevelopmental conditions) • suitable for ongoing treatment with the 6 monthly and annual reviews completed in primary care	This is a new change, now included as part of this updated LCS
Cohort 2 – Children and young people with ADHD who are receiving specialist treatment for mental health or neurological co-morbidities but can be stabilised so are **suitable for shared care**	These children and young people are receiving specialist treatment for mental health or neurological co-morbidities but can easily be stabilised with small changes. They may be seen more frequently by specialist services but may be suitable for shared care with ongoing treatment and the 6 monthly review, completed in primary care and the annual review completed in secondary care	This was already included in previous LCS and will continue – no change
Cohort 3 - Children and young people with co-morbidities and/or complex needs due to risk (mental health/ safeguarding / physical health) where **care remains in specialist services**	These children and young people may be on other forms of medication, where doses are frequently changed, and are under regular review by a specialist service. These children and young people are not suitable for shared care and prescribing responsibility stays within the specialist service.	Not included under previous LCS and remain excluded under new LCS – no change and not part of this service.

Looking forward, we will review the LCS in April and that will provide an opportunity to review.
We have already identified the need to include Epsom and Developmental Paediatricians.

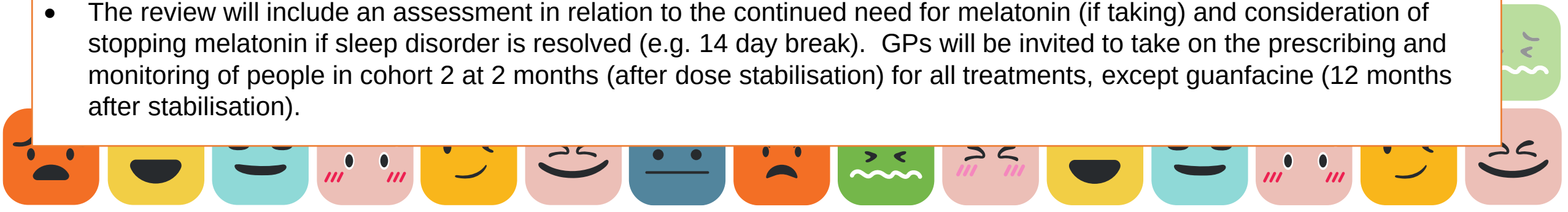
What is required by practices under this LCS and what support is available

Cohort 1: Transfer of Care:

- CYP who have been on ADHD medication for at least 12 months and are fully stable will be identified as suitable for transfer to primary care following their next 6 monthly review.
- If care is transferred, responsibilities for managing the prescribing of ADHD medications (including melatonin) will be stated so all parties are clear on their responsibilities.
- For CYP in cohort 1, the GP will need to undertake 6 monthly holistic reviews and an annual ADHD medication review.

Cohort 2: Shared Care

- As part of shared care, the practice would need to undertake a holistic review of a child's physical development in relation to their ADHD medication on a 12 monthly basis.
- The child will be reviewed 6 monthly in line with the product license, with reviews alternating between the GP 12 month review and the specialist 12 month review.
- The review will include an assessment in relation to the continued need for melatonin (if taking) and consideration of stopping melatonin if sleep disorder is resolved (e.g. 14 day break). GPs will be invited to take on the prescribing and monitoring of people in cohort 2 at 2 months (after dose stabilisation) for all treatments, except guanfacine (12 months after stabilisation).



What is required by practices under this LCS and what support is available?

How quickly would CYP transfer across to primary care under cohort 1?

- Some CYP already meet the criteria and will be ready to transfer when the LCS begins
- Staged and managed approach for transfer, with SABP providing clear communication with CYP & Family and primary care on the transfer process.
- Those who are new to the service/ medication will start in cohort 2 and after 12 months, if they meet the criteria for cohort 1 (i.e. are stable) they will move to primary care

What support will be available and where can I find out more?

- Practices will receive regular updates and links to resources for families and would also receive training
- Professional consultation line to aid referral will be available (72-hour response)
- We have time available to discuss today what other training or support would help build support for the LCS

What if further advice, a referral back into SABP or a medication review is needed?

- If, following assessment (or at any other time), a GP felt a medication review was required for a CYP in cohort 1, contact professional consultation line to allow SABP to respond in a timely way for the CYP's review timeline.
- If the child or young person goes back into the specialist service and medication is changed, they go back into cohort 2. A shared care document would be agreed based on the new medication, and they would stay in cohort 2 for at least 12 months on the new medication.

What happens for cohort 2 as the young person transitions to adult services

- This will be via the existing SABP transition protocol for CYP transitioning into adult services.
- Cohort 1 – primary care to contact Adult ND Services Advice and Guidance Line.

Guidance on adjusting medication doses

METHYLPHENIDATE

(a) Methylphenidate Immediate Release Tablets can be increased in steps of 5mg or 10mg tablets

(b) Methylphenidate Modified Release Tablets (e.g. Concerta XL, Delmosart, Affenid XL, Xenidate XL, Matoride XL) can be increased in the following steps 18mg (starting dose), 27mg, 36mg, 45mg (as 1 tablet of 18mg and 1 tablet of 27mg), 54mg, 63mg (as 1 tablet of 27mg and 1 tablet of 36mg), and 72mg (as 2 tablets of 36mg)

(c) Methylphenidate Extended Release capsules

   a. Medikinet XL can be increased in steps 5mg or 10mg capsules (the medication is available in the following capsule doses 5mg, 10mg, 20mg, 30mg, 40mg, 50mg, and 60mg capsules)

   b. Equasym XL can be increased in steps of 10mg (the medication is available in the following capsule doses 10mg, 20mg, 30mg. Thereafter, doses of 40mg, 50mg, and 60mg need to be made up by combining the earlier doses)

ELVANSE

The starting dose is 20mg capsules, and the doses can be increased in 10mg steps up to a maximum of 70mg. The capsules are available as 20mg, 30mg, 40mg, 50mg, 60mg, and 70mg

INTUNIV

The minimum dose is 1mg and the doses can be increased in steps of 1mg (allow at least 2 weeks between each dose increase) up to a maximum of 4-6mg depending on the child's age and weight (please refer to BNF)

ATOMOXETINE

The usual starting dose is 0.5mg x child's weight and increased gradually to the usual maintenance dose of 1.2 x child's weight up to 80mg per day. The capsules are available in the following strengths 10mg, 18mg, 25mg, 40mg, 60mg and 80mg.

Advice for reduced appetite

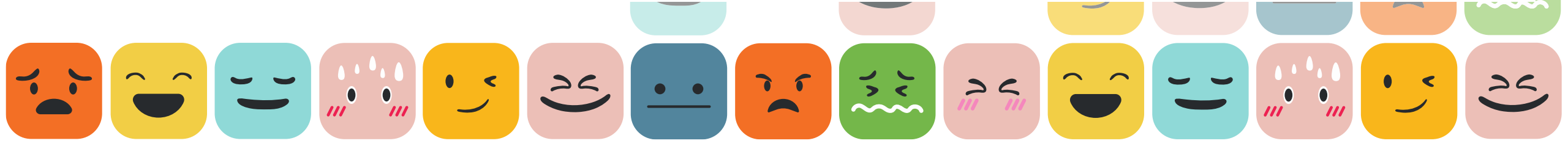
1. If the child is maintaining their weight and height centiles, then they are likely to be eating enough even if they are reporting reduced appetite. Advise the family to continue their current strategies

1. If the child is not gaining weight, advise one or more of the following
    a. Eat more at breakfast before taking the medication and more at dinner when the medication has worn off.

    b. Delay dinner until the medication has worn off and the appetite has returned

    c. Stop the medication on weekends and school holidays and encourage the child to eat more at these times (NB: This does not apply to Intuniv or Atomoxetine as these medications have to be taken daily)

    d. Offer the child their favourite snacks at lunchtime when the appetite suppression is most noticeable



Advice for sleep onset delay

1. Ensure adequate sleep hygiene e.g.
   a. Regular bedtime

   b. No electronic games or gadgets or light emitting equipment an hour before bedtime or in bed

   c. No caffeinated drinks after 12noon

   d. Give the family this website to get more information including free 1.1 support https://cerebra.org.uk/get-advice-support/sleep-advice-service/

Advice for sleep and Melatonin

- Give parents advice and guidance on sleep hygiene
- Advise parents to implement recommended measures including using a sleep diary
- Rule out other causes of insomnia (e.g. bedtime resistance, sleep disordered breathing, side effects of medication). If taking methylphenidate, seek specialist advice which may be recommendation to reduce dose or to change to atomoxetine
- First line use **melatonin 2mg prolonged release tablets** (max daily dose 10mg as per BNFc). [Off-label use]
- Immediate release **melatonin tablets (1,2,3,4,5mg strengths)** may be prescribed if an immediate onset of action is required [licensed use for children and adolescents with ADHD]. These tablets may be crushed to aid swallowing [licensed use as above].
- Note that the modified release formulation of melatonin will assist with *maintenance* of sleep, whereas the immediate release formulation will assist with promoting the *onset* of sleep.
- If child has a feeding tube in situ, or significant swallowing difficulties consider a **melatonin oral solution 1mg/ml liquid** which is alcohol and sugar free [This may be an off label use due to variation in licensing between manufacturers]**.**
- **NOTE:** For children under 5 years, the propylene glycol content and sorbitol content of their dose of liquid should be calculated to ensure it is within safe limits and a suitable licensed preparation selected for dispensing (See http://nppg.org.uk/wp-content/uploads/2020/12/Position-Statement-Liquid-Choice-V1-November-2020.pdf).
- ALL patients to continue to use sleep hygiene measures with sleep diary.

STOP treatment if ineffective

A01 - 2024 – ADHD
ADHD – 1 LCS, split into 2 documents; Cohort 1 & Cohort 2

- **Previous price:** £50.00 for one cohort
- **Previous Price:** ES: Not previously available

New Price (including new cohort):

Cohort 1 - Annual Review Appt	Per Appt	**£102.53**
Cohort 1 - 6 month review	Per Appt	**£69.58**
Cohort 2 - 6 month review	Per Appt	**£69.58**

Cohort 1	Children and young people who are **stable:** • Fully stabilised dose (i.e., titrated dose of medication which has not been changed in the recent six-month period) • uncomplicated by comorbidities (i.e., currently not receiving specialist treatment for other mental health or neurodevelopmental conditions) • suitable for ongoing treatment and six-monthly reviews in primary care
Cohort 2	Children and young people who have ADHD and are currently receiving specialist treatment for other mental health or neurological comorbidities. However, are easily stabilised with small changes but are perhaps seen more frequently by specialist services. These CYPs may be suitable for shared care.

- Limited to patients under care of SABP – but available as an LCS to practices across all SH and commissioners are exploring whether this could be extended to other providers in the future.
- Training Hub will co-ordinate training needs

More information

Ahead of the January 2025 launch of the LCS a recorded webinar will be held, providing information on the LCS and offering primary care colleagues the chance to ask any questions they may have.

A crib sheet of helpful information is being developed in partnership with GP leaders which will be shared ahead of the launch.

More in-depth training on ADHD will be co-developed to provide any additional training needs that GPs or primary care teams may feel would help them feel confident in taking on this work. The webinar will provide the opportunity to inform this offer.

- Q&A

Questions about the LCS

What further training or support would primary care find helpful?

What's new or different in this LCS?

- Under the updated LCS, there are 3 identified cohorts for CYP with an ADHD diagnosis.

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- 13 year old presenting with inattention and poor functioning at school
- Assessed and ADHD confirmed
- Medikiinet XL 10 mgs treatment initiated
- Initial benefit of better concentration at school and less sense of fidgetiness but insufficient improvement
- Increase dose to 20mgs
- Resolved symptoms
- Transferred to GP
- Review in Primary care as per LCS at 6mths and 12mths
- Access and advice available if needed

- 16 year old with suspectd ADHD and depression
- Assessed - ADHD and depression confirmed
- Medikiinet XL 10 mgs treatment initiated
- Initial benefit of better concentration at school and less sense of fidgetiness but insufficient improvement
- Increase dose to 20mgs
- Resolved symptoms
- Transferred to GP for ADHD repeat prescribing
- Comorbid needs continue to be met by specialist teams
- ADHD review in GP at 6mths
- ADHD Reviewed in specialist teams at 12mths
- Advice and guidance available to GP throughout