Commissioning support toolkit for Integrated Care Systems: improving care and outcomes for children and young people

Version 6.0, March 2025

Contents

Background

Children and young people (CYP) represent a third of England's population. Identifying and meeting their needs at the earliest opportunity is vital to giving them the best possible start in life and to improving the future health of the population.

Evidence indicates that interventions in childhood are likely to be more effective at reducing the risk of developing a chronic disease across the life course compared with interventions in adulthood. The early years provide a crucial window to improve health, bringing short and long-term benefits to individuals, population health and the economy, avoiding the greater challenge and expense of intervening later in life.

Since the publication of the NHS Long Term Plan (LTP), progress has been made in delivering on key priorities to improve the health and wellbeing of children and young people. However, despite areas of progress, Lord Darzi's Independent Investigation of the National Health Service in England highlighted the ongoing significant challenges facing children and young people, including:

- The health and care needs of children are becoming increasingly more complex. The number of children with eight or more chronic conditions were found to have nearly double between 2012 and 2019.
- 5 million children in England are affected by excess weight or obesity and health inequalities begin at a very young age, for example, children from the most deprived decile are 2.1 times as likely to be obese in Reception than children from the least deprived decile.
- The prevalence of mental health disorders has increased from around 1 in 9 in 2017 to 1 in 5 children and young people (aged 8-16) in 2023.
- There has been a rising trend in the number of children living in poverty since 2018/19.
- There has been an exponential growth in demand for ADHD and autism assessments since 2019.

Established to support delivery of the commitments for children and young people set out in the NHS Long Term Plan, the CYP Programme has developed and tested targeted interventions, working closely with ICBs and evaluators, to improve the health and outcomes for children and young people, and to build an evidence base for commissioners.

The interventions set out in this toolkit describe evidenced interventions that Integrated Care Boards (ICBs) can roll-out to improve the health of their local CYP population. The initiatives are aligned to the Government's goal of delivering reform against three stated shifts: to move care from hospital to community, from treatment to prevention, and from analogue to digital. As such, they support the broader direction of travel laid out by the Government, including the key ambition to raise the healthiest generation of children ever.

Purpose of the toolkit

This toolkit brings together the evidence to date from intervention test sites led by the CYP Transformation Programme. It sets out examples of the interventions that will make the required improvements. It will be used to support ICBs in meeting the needs of their local population, scaling up good practice and making evidence based commissioning decisions.

The toolkit will continue to be updated as further evidence becomes available.

Audience

This toolkit is aimed at ICBs, specifically commissioning teams, Executive Leads for Children and Young People, as well as finance, strategy and transformation leads, to inform planning and resource prioritisation.

Contact

If you have any questions or would like more information on any of the interventions set out in this toolkit, please contact the Children and Young People's Programme at: england.cyptransformation@nhs.net

Asthma Nurse Specialists

Case for Change

Asthma is the most common long-term medical condition in children in the UK, with around 1 in 11 children and young people living with asthma. The UK has one of the highest prevalence, emergency admission and death rates for childhood asthma in Europe, with marked inequalities. Outcomes are worse for children and young people living in the most deprived areas, with mortality rate four times higher for children living in the most deprived neighbourhoods of England (2.66 per 1 million children) compared to the least deprived (0.68 per 1 million children). Additionally, children living in the poorest 10% of areas are four times more likely to have an emergency hospital admission than those in the least deprived 10% (Asthma and Lung UK, 2023).

Asthma is a long-term condition but can be perceived as a mild disease and research shows that it is often not taken seriously enough. A study showed that 1 in 6 people in the UK do not know, or are unsure, if the condition can be fatal.

NHS England's ambition is to reduce avoidable harm to children and young people from asthma and improve their quality of life. This can be achieved by taking a whole system approach to asthma management that includes addressing environmental triggers, a comprehensive education programme, promoting personalised care, effective preventative medicine, and improved accuracy of diagnosis. Developed in close collaboration with clinical and patient experts, the National Bundle of Care for children and young people with Asthma was published in September 2021.

Short description of pilot programme

NHS England piloted the addition of two specialist children and young people Asthma Practitioners in 8 pilot sites across the 7 NHS England regions. These practitioners worked across their ICS to deliver care to children and young people with asthma across primary, secondary, and tertiary care.

A risk stratification tool was piloted to identify those children and young people at risk of adverse asthma outcomes to enable effective targeted interventions. The Practitioners also focused on reducing health inequalities, improving local knowledge on children and young people asthma and upskilling the healthcare workforce for long term change and improvement.

Objectives of the intervention

- Reduction in asthma admissions
- Reduction in asthma emergency attendances
- Reduction in overall health inequalities
- Education and upskilling of local healthcare teams
- Development of local asthma network

- Strengthening partnerships with schools, local authorities, education and public health teams

Evidence base

- National Review of Asthma Deaths (2014)
- National Respiratory Audit Programme

Finance

- Additional resource within the system:
    - Band 8a – Service Manager
    - Band 7 – Project Manager/Officer
- Clinical time allocation for upskilling sessions for healthcare practitioners

Data and Metrics

National

- Asthma admissions
- Asthma Emergency Department attendance
- Asthma Readmissions
- Training data
- Dispensing data

Data on CYP asthma admissions, attendances, readmissions and reattendances can be accessed through the CYP transformation programme dashboard, which also includes dispensing data.

Local

- No. of Annual reviews
- No. of children with asthma action plans
- Primary care attendances due to asthma
- Fatalities
- Local dispensing data (CYP with SABA +/- ICS)
- Seasonal flu vaccinations
- No. of asthma friendly schools
- Monitoring of deprivation index and ethnicity index

Emerging findings / trends

- Key learning from the pilot has been the importance of having an ICB led strategy for asthma and using that strategic approach for impact on asthma outcomes

- Risk stratification is a valuable tool to identify marginalised children and young people and those who are at the highest risk due to modifiable risk factors. The risk stratification process can be built into Primary Care systems
- The importance of senior leadership was highlighted, including asthma clinical lead, CYP Programme and local leadership (e.g. Primary Care leads, Community Practitioners, Local Authority, Housing, Schools)
- The development of an ICS based asthma network has the potential to improve asthma management, share learning and strengthen collaboration
- Upskilling and training all levels of the community healthcare team is the most sustainable way to impact asthma outcomes.

Resources

- National Bundle of Care for CYP with Asthma
- Overview | Asthma pathway (BTS, NICE, SIGN) | Guidance | NICE

Epilepsy Mental Health

Case for Change

Epilepsy affects an estimated 112,000 children and young people in the UK and is the most common neurological disorder in children and young people. It is characterised by recurrent seizures. Most individuals can maintain satisfactory control of the seizures through the use of antiepileptic drugs; however, some children and young people may benefit from epilepsy surgery.

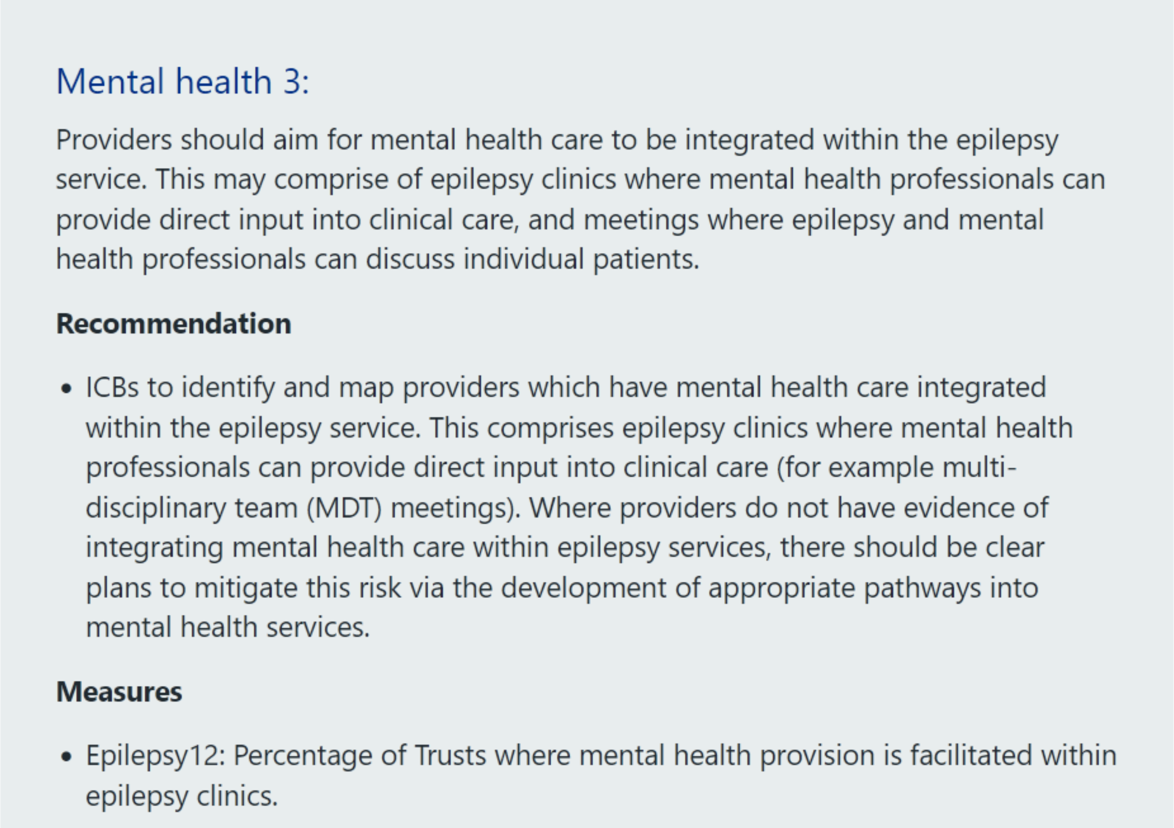
Children and young people with epilepsy have an increased incidence of mental health conditions including anxiety and depressive disorders when compared to the general population and those with other long term conditions. For example, some studies have shown that 37% of children and young people with epilepsy have mental health problems compared to 9% in children and young people with diabetes and 7% of healthy peers.

Despite this, data from the most recent Epilepsy12 audit (Cohort 5) shows that only 22% of Trusts formally screened for mental health disorders, and only 18% of Trusts had some form of co-located mental health provision, the latter as recommended within the NHS England Paediatric Epilepsy best practice criteria (BPC). In addition, only 61% of children and young people with epilepsy and a mental health problem had evidence of receiving mental health support, while 26% of Trusts did not have agreed referral pathways into mental health services.

Without early identification, through screening and subsequent referral/management, these problems can lead to increased morbidity and reduced quality of life, treatment outcomes and educational attainment. Epilepsy can also affect the family of children and young people, with parents/carers more vulnerable to anxiety and depression.

There are significant pressures on Child and Adolescent Mental Health Services (CAMHS) where some of these children and young people may need onward referrals to. In addition, when children and young people are seen in CAMHS, there is sometimes a false perception that generic mental health services may not be appropriate as the problems are related to a physical health condition and its treatment. This may lead to referrals not being accepted or delayed.

NHS England published a ‘bundle of care’ for CYP epilepsy in 2023 in which it was recommended that providers should seek to integrate mental health care within epilepsy services:



Mental health 3:

Providers should aim for mental health care to be integrated within the epilepsy service. This may comprise of epilepsy clinics where mental health professionals can provide direct input into clinical care, and meetings where epilepsy and mental health professionals can discuss individual patients.

Recommendation

- ICBs to identify and map providers which have mental health care integrated within the epilepsy service. This comprises epilepsy clinics where mental health professionals can provide direct input into clinical care (for example multi-disciplinary team (MDT) meetings). Where providers do not have evidence of integrating mental health care within epilepsy services, there should be clear plans to mitigate this risk via the development of appropriate pathways into mental health services.

Measures

- Epilepsy12: Percentage of Trusts where mental health provision is facilitated within epilepsy clinics.

Short description of pilot programme

Psychology Adding Value Epilepsy Screening (PAVES) is an innovative model of care developed and piloted within NHS Lothian. It consists of mental health screening within routine epilepsy clinics alongside a stepped care intervention pathway. The screening identifies potential psychological, social and behavioural difficulties during routine epilepsy clinic attendance, as well as early identification of risk. It uses a traffic light metaphor where questionnaire scores are automatically RAG-rated to guide medical clinicians' understanding and further investigation. The traffic lights map to appropriate, stepped, early intervention options.

Interventions may include: signposting to ratified third sector (VCSE) organisations; self-help materials; communication with schools; parent workshops; a six-week psychosocial group for adolescents (PIE-r); and the MICE intervention ("Mental Health Intervention for Children and Young People with Epilepsy").

Pathway mapping was supported through a national partnership with a digital mental health support database provider, Hub of Hope. This had the added benefit of supporting wider services beyond the pilot, as well as an alternative avenue for CYP to self-direct towards relevant VCSE services.

To support the delivery of PAVES, a desktop digital screening tool was designed by Tactuum. The tool involves the child or young person completing a screening, with scored results then directly sent to clinician's/service's e-mail inbox. The automatic scoring/RAG-rating also clearly highlights the difficulties that the family is struggling with.

Funding was made available to systems to pilot a model of care based on PAVES within a system footprint. Regions were asked to determine where best to target funding based on an analysis of current practice within systems, current models of integrated mental health and epilepsy care, and readiness to mobilise improvement plans.

Objectives

- Use the PAVES model as a template for testing an integrated mental health approach within epilepsy services.

Evidence base

- A health economic analysis of the PAVES pilot was undertaken by the Scottish Health Technologies Group within Health Improvement Scotland (HIS). It found that per 100 patients screened, PAVES could avoid 26 referrals to CAMHS compared to standard practice and save nearly £30,000.
- CYP who meet diagnostic criteria for a mental health disorder, as identified through PAVES screening, may also be treated via the MICE intervention (Mental Health Intervention for Children and Young People with Epilepsy). This is a standardised manual-based intervention with specific content to be covered within 12-16 hours of intervention over a six month period. A randomised controlled trial has shown it to be effective in reducing mental health disorders in CYP aged 3-18 with epilepsy who have anxiety, depression and/or behavioural problems (or a combination), including those with intellectual disabilities and autism.
- A recent economic analysis has also shown this intervention to be cost-effective.

Emerging findings / trends

- In the South West, the pilot has led to significant enhancements in mental health care delivery, demonstrating significant impact on patient care and service efficiency. Outcomes include:
  - Improved assessment practices and increased use of standardised screening tools
  - Better identification and categorisation of mental health conditions
  - Increased frequency and clarity of mental health discussions and referrals
  - Diversification of services accessed, providing families with a wider array of support options

    - Strengthened interdisciplinary collaboration between Epilepsy Specialist Nurses (ESNs) and neuropsychology specialists

- Feedback from children and young people involved in the (Acceptance and Commitment Therapy) group:

  "It's been a brilliant experience being able to work towards creating the sessions and the booklets. The therapy groups would have helped me so much, especially when I was first diagnosed. It's creating a safe space for young people to meet others and talk about things that are affecting them"

  "I think if I would've had this support earlier on in my journey it would've stopped some more serious mental health issues happening"

Finance

Embedding the PAVES within a system-level footprint would typically require a Band 8a Clinical Psychologist (0.6 WTE) and a Band 5 Children's Wellbeing Practitioner (0.4 WTE).

Both the ACT group and PIE-r interventions have no ongoing costs, and the materials are free to use. For further information/materials on ACT, please contact research@youngeplilepsy.org,uk. For PIE-r, contact Prof Liam Dorris: Liam.Dorris@glasgow.ac.uk.

For any further queries in relation to Tactuum, the designers of the desktop digital screening tool, please contact Mark Buchner (mbuchner@tactuum.com). ***Please note*** *that we are sharing this for information purposes only. ICBs/Trusts will need to follow their commercial process when assessing and procuring any solution.*

Data and Metrics

We would encourage ICBs to consider the following projected outcomes:

Indicator	Source
% of children with epilepsy where there is documented evidence that they have been asked about mental health either through clinical screening, or a questionnaire/measure	Epilepsy12
% of children with epilepsy and a mental health problem who have evidence of mental health support	Epilepsy12
Number of CYP with evidence of input from clinical psychologist/other mental health professional	Epilepsy12
Number of referrals into CAMHS services	Local reporting
Number of referrals/signposting to VCSE services	Local reporting

Number of CYP offered, and number of CYP participating in, a psychosocial group intervention	Local reporting
Number of CYP with mental health disorders offered and participating in evidence-based treatment for their mental health (e.g. MICE)	Local reporting
Number of parents/carers offered, and number of parents/carers participating in, Parent/Carer Workshops	Local reporting

To note, the lead time for setting up these pilots was significant as they have effectively established new models of care, involving embedding staff; developing new pathways; system mapping; training; digital setup; new governance and local agreements.

Resources

- National bundle of care for children and young people with epilepsy
- Case studies on integrated mental health care (Appendix 5)
- Hub of Hope (mental health support directory to support pathway mapping element; option to filter for ‘epilepsy-friendly’ services)
- Published study on efficacy of PIE-r intervention, Epilepsy & Behavior, 2017
- Published study on efficacy of MICE intervention, The Lancet, 2024

Epilepsy Nurse Specialists

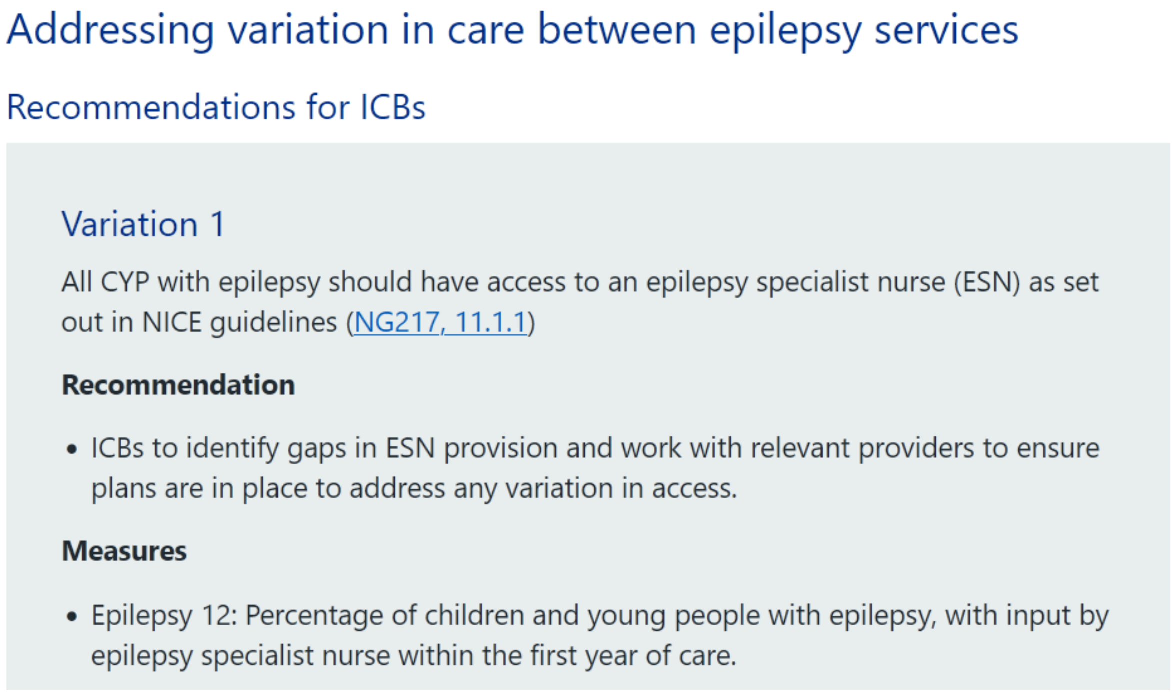
Case for Change

All children and young people with epilepsy should have access to an epilepsy specialist nurse (ESN) as set out in NICE guidelines (NG217, 11.1.1). Whilst there have been improvements, there remains variation within ICBs on access to ESNs within the first year of care.

Epilepsy is one of the five key clinical priorities within the CYP CORE20PLUS5 framework. Within this, increasing access to ESNs for children and young people from the most deprived quintile, and those with learning disabilities and/or autism, is a key improvement priority and metric.

Reducing emergency admissions for children and young people with long-term conditions including epilepsy is included within the NHS Long Term Plan, alongside improving the quality of care for children and young people with epilepsy and supporting the integration of paediatric skills across services.

NHS England published a 'bundle of care' for CYP epilepsy in 2023, in which it was recommended that ICBs identify gaps in ESN provision and work with relevant providers, to ensure plans are in place to address any variation in access (see relevant section of bundle below):



Addressing variation in care between epilepsy services

Recommendations for ICBs

Variation 1

All CYP with epilepsy should have access to an epilepsy specialist nurse (ESN) as set out in NICE guidelines (NG217, 11.1.1)

Recommendation

- ICBs to identify gaps in ESN provision and work with relevant providers to ensure plans are in place to address any variation in access.

Measures

- Epilepsy 12: Percentage of children and young people with epilepsy, with input by epilepsy specialist nurse within the first year of care.

Short description of pilot programme

NHS England funded a number of Epilepsy Specialist Nurses with a specific focus on integration and continuity of care for patients across organisational boundaries. The typical model was comprised of 2x Band 7 and 1x Band 8a ESN posts. Regions were asked to determine how to allocate this spend to systems based on analysis of workforce data from Epilepsy12 and readiness of systems to mobilise. The specific blend of banding and WTE varied depending on local set-up of services. The specific model of care was dependent on local context. For example, an ESN may be placed within a Host Trust to:

a) Manage a complex case-load of children and young people with epilepsy who require co-ordination of care across multiple settings and services. This may be a case-load within the Host Trust alone and/or from wider Trusts within the locality, dependent on capacity

And/or:

b) Undertake wider system-level roles to support horizontal and vertical integrated care

Examples of the wider system-level roles undertaken may include:

- Ensuring, and establishing where required, relevant referral pathways into services such as mental health care, tertiary neurology and neurodevelopmental services.
- Supporting transition of young people into adult epilepsy services, specifically young people with complex epilepsy requiring a multidisciplinary team approach
- Liaising with community paediatric services in the management of children and young people with learning disabilities and autism. For example, this may include establishing and supporting any out-reach clinics in residential school settings
- Developing a sustainable model for training schools in the use of emergency medications
- Support consenting processes required for genomic investigations

Objectives

Demonstrate the value of ESNs working across a system and traditional healthcare-setting boundaries; increase the supply of skilled ESNs.

Evidence base

- NICE guidance published in April 2022 states that all children and young people with epilepsy should have access to an epilepsy specialist nurse. There is clear evidence to show that access to ESNs result in:
    - Decrease in emergency paediatric epilepsy admissions

    - Improving knowledge, self-care and quality of life for children and young people
    - Supporting continuity of care between settings
    - Cost savings, both long-term and within the first year of care
- A NICE evidence review around the cost effectiveness of ESNs determined that children and young people with epilepsy receiving an ESN-led intervention incurred £2,468 lower costs at 1 year than a non ESN-led intervention.
- A recent economic evaluation has shown a direct correlation between ESN numbers and achieving care planning outcomes.

Emerging findings / trends

Impact from Hull and East Riding:

- New patient pathway developed resulting in reduction of approximately 250 consultant follow-up appointments, delivering cost-savings alongside consistent quality of care.
- Hospital admissions/appointments prevented through epilepsy medication changes through ensuring access via direct contact between nurse and patient.
- Mapped out the transition pathways jointly with paediatric and adult MDTs, including bespoke support for young people with varying levels of complexity.
- Resource leaflets around transition have been developed and adopted as national standard.
- Current nursing structure has allowed team to support vagal nerve similar pathway locally, resulting in 80 fewer appointments for review within a stretched Tertiary Neurology service and preventing families from having to travel 120 miles to another hospital for treatment.
- Additional capacity has allowed team to maintain accurate and regular data entry for the Epilepsy12 audit.

Finance

The above model would typically require two WTE Band 7 and one WTE Band 8a ESNs.

Data and Metrics

Indicator	Source
% of children and young people with epilepsy, with input by epilepsy specialist nurse within the first year of care.	Epilepsy12
% of children and young people with epilepsy after 12 months where there is evidence of a comprehensive care plan that is agreed between the person, their family and/or carers and primary and secondary care providers, and the care plan has been updated where necessary	Epilepsy12
Total WTE epilepsy specialist nurses	Epilepsy12
Number of Trusts with at least some level of input from an epilepsy specialist nurse	Epilepsy12
Unplanned hospitalisation for epilepsy in those aged under 19	SUS data
Results from Friends and Family Test or similar PREM	Friends and Family Test or similar
Number of patient contacts: -Face to Face -Telephone/virtual	Local reporting
Case studies from community of practice	Community of Practice

Resources

National bundle of care for children and young people with epilepsy

The following may also support in the delivery of this recommendation:

- Best Practice Tariff, 2023/25: Paediatric Epilepsy
- Core20PLUS5 for CYP

Integrated care for children and young people

Case for Change

The wellbeing of children and young people is to do with more than health – education and wider local services play a key role. Health and care may be provided by various organisations including by NHS services, schools, local authority and social care professions and across different providers. This can lead to care being fragmented, difficult to access and not based around the child or their parent's/carer's needs. Integrating services for children and young people can reduce repetition, delay, confusion and duplication.

The ambitions for NHS England's CYP integration programme emerged out of the NHS Long Term Plan. The pilot programme tested various models of integrating care for CYP to identify success factors and key themes of good integration. An external evaluation was commissioned to gather evidence and inform long term policy recommendations on the integration of CYP services.

Shifting care from hospital to community through the development of a neighbourhood health service is a key priority for the Government. Neighbourhood health guidelines published in January 2025 set out the six core components of neighbourhood health models. One of these components is the neighbourhood multidisciplinary team (MDT). The learning from the integration test sites has informed the policy development around neighbourhood health for children and young people. The Guidance on neighbourhood multidisciplinary teams for children and young people published alongside the wider document, provides further details for this core component, specifically for children and young people.

Short description of pilot programme

15 pilot sites were appointed across England to pilot four types of integrated models of care over a 2-year period:

- **Enhanced primary care:** place-based interventions driven from primary care that enable professionals to work together to provide holistic information, care and support.
- **Access to therapies:** interventions delivered at Local Authority or ICS level to improve access to support for children with special educational needs and/or disabilities.
- **Pathway-specific integration:** focused on specific long-term health conditions.
- **System-wide infrastructure development:** pilots explicitly focusing on ways of working to spread and share best practice.

Some pilots operated across an ICB footprint; others operated at neighbourhood level.

Implementation was characterised by three distinct but overlapping phases:

- Set up and engagement: understanding the problem and aligning local stakeholders around potential solutions (all pilots).
- Establishing integrated working processes: including data sharing, staffing and financial practices (all pilots).
- Integrated care delivery: interventions that CYP and families would experience as integrated, for example joint clinics and MDT discussions (six pilots).

Objectives

The overarching aim of the programme was to develop an evidence base for what 'good integrated care for CYP looked like', this included:

- Identify success factors when developing integrated models of care
- Enabling the scaling-up of key themes and principles of integration
- Articulating what integration means for CYP

Ipsos UK, supported by the NHS Strategy Unit, were commissioned by NHS England as an evaluation partner. A mix of deep dive quantitative and qualitative evaluation was undertaken with some pilot sites, with lighter touch qualitative evaluation from other sites.

Some pilot sites also undertook local evaluations with academic partners including Bird et al (2024). 'Exploring the impact of integrated health and social care services on child health and wellbeing in underserved populations: a systematic review'. Available from: https://doi.org/10.1101/2024.01.05.24300706

Key findings

- The programme demonstrated the potential of integrated models of care to achieve national and local system priorities for improved professional experience, reduced health service use and improved CYP and family experience, particularly for those most at risk of health inequalities.
- Implementation was most successful in the pilots that struck a balance between top-down strategic direction and bottom-up, locally driven, solutions.
- All pilots aimed to improve the experience of care for CYP and their families. The outcomes observed in the health domain have been in large part due to more timely and coordinated information to CYP and the people supporting them as a result of improved multiprofessional working. Two sites (Portsmouth and Birmingham Sparkbrook) were able to point to evidence of reduced waiting times. Two of the pilots (Birmingham Sparkbrook and North Solihull) specifically described identifying and addressing unmet needs through their more holistic-focused interventions that bring different professionals together to explore the multiple factors underlying poor health and wellbeing.

- Outcomes were strongest in the workforce domain, with strong and widespread evidence of perceived improvements in local system relationships and information sharing. All pilot sites reported improvements in their workforce’s:
    - Knowledge and skills
    - Relationships
    - Communication and joint working across the system
    - Governance and strategic leadership
    - Capacity (and workload)
    - Staff motivation and job satisfaction.

Finance

Evaluation found emerging evidence of cost savings across a number of pilot sites. For many pilots, it is too early to estimate cost savings, but North Solihull and Birmingham Sparkbrook savings have been quantified. Both pilot sites delivered enhanced primary care/ MDT integrated models of care:

- North Solihull ICB estimated savings (based on 427 CYP referred up to April 2024):
    - 569 GP appointments saving approx. £17,000
    - Reduced need for outpatients' appointments for 12% of CYP, saving £10,400
    - 5124 hours of support provided outside clinical/therapeutic support, saving over £400,000
- Birmingham Sparkbrook pilot – estimated cost per clinic as £70, compared to first appointment in general paediatric outpatients at £325. Savings of £44.08 per patient.

For pilots within the ‘enhanced primary care’ typology, there is evidence from similar interventions that have been running for a longer period and over a larger geography that this can be achieved, with projected cost savings. This includes the Connecting Care for Children programme delivered in North West London.

Resources

- Ipsos Mori (2024). ‘Children and young people integration pilots: national programme evaluation’. Evaluation report for NHS England.

Youth Workers

Case for Change

Many children and young people with long-term conditions and/or mental health needs present with concerns that require holistic care. Clinical staff may not always be best positioned or have capacity to support children and young people’s wider needs associated with their condition. Youth Workers are uniquely placed to bridge the gap between children and young people, their families and health professionals. Embedding Youth Workers in hospital settings offers an opportunity to provide additional support to children and young people and clinical teams that look after them. Although there are existing pockets of positive practice, more evidence is needed on the impact of youth work in hospital settings and benefits to children and young people and the NHS. This pilot’s aim was to contribute to the evidence base and support development of the Youth Worker role in hospital settings.

Short description of pilot programme

The Youth Workers support children and young people aged 11-25 within acute care environments and the community. The areas of focus for the youth workers include mental health needs and long term conditions e.g. diabetes, asthma and epilepsy. The primary purpose of the pilot was to improve the overall well-being and experience of children and young people in acute care settings by:

- Embedding specialised youth workers who understand the unique needs of children and young people with long term health conditions and mental health needs into acute settings.
- Fostering a more comfortable and responsive healthcare environment for children and young people.
- Building a rapport with children and young people outside of appointments with doctors and nurses.

Objectives

- Provide non-clinical support for young people with long-term conditions and/or mental health needs, fostering a more responsive healthcare environment.
- Realise the anticipated benefits of youth work for children and young people in acute settings such as improved experience for children and young people and their families/carers, reduction in reattendance/readmission rates and missed appointment, increased adherence to treatment.
- Assess the impact of Youth Workers in acute settings and identify positive practice through an independent evaluation to support scaling up.

Evidence base

Research by Donna Hilton has detailed the evolution of youth workers in hospital environments, emphasising the importance of addressing the unique challenges faced by adolescent patients. Youth workers can provide essential support during hospital stays. This approach not only aids in the patient's development but also enhances their overall hospital experience.

A literature review of studies (Marshall and Waring, 2021) suggests that the youth worker role in the hospital setting has a positive impact upon the lives of young people through the interventions the youth worker employed when working with young people. However, it highlights the necessity for additional empirical evidence in both quantitative and qualitative research in order to gain a greater understanding of what the youth worker role in the hospital provides to young people and the impact of their interventions from the perspectives of young people, parents, youth workers and members of the multi-disciplinary team.

Emerging findings / trends

The pilots have been live since October 2023 with staggered mobilisation across each site, ending in March 2025 with a full evaluation expected in July 2025.

Emerging evidence indicates that the youth workers in healthcare settings have a marked positive impact on children and young people as well as clinical staff. The presence of the youth worker can lead to increased engagement in clinics, improved school attendance and a reduction in repeat A&E attendance.

Early impressions from initial interviews indicate:

- Young people are very positive about the support they’ve received.
- The key benefits is long term and highly flexible support.
- Clinical colleagues are very positive about the impact on young people they work with, such as reduced referrals to CAMHS and supporting young people to attend appointments that they otherwise would miss.

To note, these findings are not based on systematic analysis of the data, but are some of the themes that stood out when reflecting across the interviews:

Finance

The total funding per site was £320k per annum to either enhance existing services or to establish a new youth work services. Youth Workers were typically employed on Band 6 contracts.

Data and Metrics

The impact analysis of the evaluation will use national datasets, the metrics to be tested within the final report include:

- Was Not Brought (WNB) rates

- A&E presentations
- Emergency admissions
- Readmission rates

Resources

Evolution of a youth work service in hospital - PubMed

“They Make Heavy Stuff Lighter.” Youth Workers in the Hospital Setting: A Service Evaluation: Comprehensive Child and Adolescent Nursing: Vol 46 , No 1 - Get Access

Family Support Workers

Case for Change

Each year in England, nearly 500,000 children aged 0-14 reattend A&E within seven days, representing about 8% of total attendances. Reducing these reattendances by just 5% could save the NHS £3.225 million annually. Local data from pilot sites also highlight the significant impact of 'frequent fliers'—families who reattend after seven days, with some children presenting up to 18 times a year at an individual cost of £2,322. These high-utilising families are a priority for early intervention, and addressing their needs could conservatively release £10 million in savings across the NHS.

Evidence suggests that targeted, proactive interventions for families frequently accessing unplanned care can reduce A&E attendances and improve health outcomes, particularly for minor childhood illnesses. Early results from smaller-scale pilots demonstrate the positive impact of embedding Family Support Workers (FSWs) in A&E settings, showing considerable potential for reducing frequent reattendance and supporting better overall family health.

Family Support Workers provide an intervention and not just signposting. They can provide education, emotional support and parenting skills as part of their roles. They can navigate both health and social care services, enabling them to truly provide holistic support to families with young children. As part of their role within healthcare settings, they can provide health literacy, make families aware of useful resources and build confidence in families to manage minor illnesses. They are generally recruited from the local area and so have a wealth of knowledge about the area and services, making it easy for them to signpost families to appropriate support, such as family hubs.

Short description of pilot programme

The CYP Programme commissioned Barnardo's to embed FSWs in A&E departments and evaluate the impact of the intervention on the families and local services. As part of this initiative, teams of three FSWs were embedded across seven A&E sites, strategically selecting locations based on local data to address areas of greatest need. The FSWs support children and families with children aged 0-11 using an in-reach model. Some FSWs are stationed directly within the A&E, while others operate in the community.

The level of support provided is tailored to each family's needs. This ranges from initial signposting and light-touch phone interventions to more intensive home visits, ensuring families receive the right level of assistance at the right time.

Objectives

- Reduction of avoidable and repeat A&E attendances for under 11's
- Support children with their nonclinical needs which may lead to avoidable A&E attendance
- Create sustainable change by improving the health literacy of parents

Evidence base

- Barnardo's piloted the Family Support in A&E model at the Lister Hospital in Hertfordshire January-June 2022; which was independently evaluated by Oxford Brooks Institute of Public Care.
- Barnardo's also has a team of FSWs based in Birmingham Children's Hospital A&E department with the responsibility for coordinating the Early Help Offer to families within the hospital.
- There was high engagement with the FSW in A&E service, with 91% of referred families engaging with the support offer.
- Self-reporting by the families against a set of outcomes collected by FSWs suggests that there were improvements in key areas including: parental confidence (87%) and parental access to child health-related information (84%).

Emerging findings / trends

There is strong qualitative evidence to support the impact of the pilot in improving outcomes for patients, this includes:

- Reduced social isolation
- Increased parent/carer confidence/resilience/health
- Improved mental health and wellbeing
- Better access to support services
- Improved understanding of parent/child illness or disability

ED staff also recognised the benefits from having FSW based within Paediatric A&E:

- FSWs act as a much-needed safety net for families, providing families with support needs that were otherwise falling between the gaps, leading to an improvement in families' moods and attitudes.
- Improving the families' agency over time, enabling them to take greater control of their health and social care decisions.
- Beneficial to the wellbeing of A&E staff by reducing their workload, and the knowledge that the families' wider needs were being met by competent professionals, without A&E staff having to signpost or chase services.

Finance

For many pilots, it is too early to estimate cost savings, however early emerging evidence has found cost savings on social impact due to the presence of a family support worker.

The total funding per site was £200k per annum, this included the costs incurred for commissioning a VCSE delivery partner.

Data and Metrics

The impact analysis for the evaluation will use national datasets, with the following metrics:

- Percentage of low-acuity A&E presentations of children aged 12 and under diverted to more appropriate care settings
- Repeated avoidable A&E presentations
- Unplanned hospital admissions for children aged 12 and under per 1,000 children aged 12 and under
- Number of A&E attendances for minor childhood illnesses for children aged 12 and under per 1,000 children aged 12 and under
- Number of emergency admissions for long term conditions for children aged 12 and under per 1,000 children aged 12 and under

The final report will be completed and shared in July 2025.

Resources

Links to published evidence will be provided in due course.

Early Years

Case for Change

- The UK has one of the highest prevalence, emergency admission and death rates for childhood asthma in Europe.
- 1 in 3 children leaving primary school are overweight or living with obesity.
- Within the most deprived quintile, 34% of children aged 5 experienced tooth decay, compared with 14% in the least deprived quintile.
- On average, there was a relative 10% increase in risk of death between each decile of increasing deprivation.
- Tooth decay is almost entirely preventable - tooth decay is the number one cause of admission to hospital for 5-9s.
- 50,000 0–5-year-olds are admitted to hospital each year for non-intentional injuries.
- 7% of health visitors felt confident that all families would be able to access support. 86% said there's a lack of capacity in other services to pick up referrals.

The NHS Long Term Plan (LTP) set out a vision for the future of the NHS, highlighting the importance of a strong start in life for children and young people. More recently, the Government set out a bold ambition to create the 'healthiest generation of children in our history', with a 10 Year Health Plan shifting focus of delivery from hospital to community and from sickness to prevention.

Several work programmes are running across the sector with a focus on early years. Although the primary aim of each of these programmes of work is different, there is a real opportunity to build on existing partnerships and join up care across the early years, health, local authority and the voluntary sector to enhance the early years offer through an intervention-led approach.

Leveraging and building on the development of Integrated Care Partnerships (ICPs), ICBs and Family Hubs, offers an opportunity to ensure there is a real focus on prevention to reduce health inequalities by proactively identifying and delivering tailored support for groups who are at risk of poorer healthcare access, experience and outcomes.

Short description of pilot programme

11 pilot sites were funded across 7 NHS England regions to generate evidence around a targeted, enhanced, intervention-led offer across the early years. Pilots have tested models of enhanced early years care, covering a range of clinical policy areas.

Interventions have been implemented by a range of early years professionals, including public health nurses, community connectors and parent champions, based on local requirements. Projects utilised a theory of change and logic model development approaches to generate outcomes.

Objectives

- In the short-term:
    - Reduce unplanned hospital attendances and admissions
    - Improve health literacy, support families' access to wider social support
- In the longer-term:
    - Reduce infant mortality
    - Reduce tooth decay
    - Improve wellbeing

Emerging findings / trends

Key learning from pilot areas indicates that holistic, integrated early years health interventions help address the widening of health inequalities and improve health for CYP and families known to be at the greatest risk of poor outcomes or late/emergency healthcare use, particularly if interventions are combined with assertive outreach, training and partnerships with Early Years, Social Care and Health services.

Activities delivered:

- **Integrated Working within Health and Early Years**
    - Over 400 1:1 sessions delivered across a range of topics, including housing support, emotional wellbeing, support at appointments with professionals, education, as well as provision of baby equipment.
    - Challenging health inequalities - 100% of referrals were families living within the highest quintiles of deprivation. Referrals ranged from self-referral, GPs, midwives, health visitors, family hubs or other statutory services.

- **Promoting Health Literacy**
    - Healthy habits workshops delivered with 194 parents/carers on eating habits, routine and boundaries. 60 CYP attended workshops on healthy eating, staying active, sleep, and mental wellbeing for families.
    - Trauma-Informed Safer Sleep Project and Tool to support health professionals in delivering trauma-informed care concerning risks related to infant mortality, through educational outreach to families most in need. 89% of participants reported that accidents or unintentional injuries in the home were less likely following the intervention.
    - Behavioural coaching and group programme has enhanced health literacy in parents, reducing maternal anxiety, and fostering healthier family environments. Successfully engaged 82.9% of targeted families, demonstrating the importance of integrated service delivery during the first 1001 days.

- **Asset Based Approaches**
    - Co-production with communities on healthcare needs and barriers to access. Recruitment to local workforce e.g. Health and Community Link Workers, a Perinatal Mental Health Prescriber, Community Connectors, Parent Champions

    (volunteers), to actively support families via 1:1 home visits and community support.

- **Training, Pathway Development and Sustainability**
  - 1,310 members of the early years workforce trained, including Healthy Child Programme 0-19s team, on topics such as general paediatrics and oral health key messaging.
  - 6,267 families directly supported on oral health for children. Oral health packs, including 26,811 toothbrush packs have been distributed
  - Access to dentist - 32 families (including 48 children) have been supported with direct access to a General Dental Practice. 421 families signposted to dental services.

Finance

Pilots cost per year ranged between £88K – 450K based on system priorities and pilot spread. Example costings:

- **Improving Health Access and Health Literacy:** a model developing integrated working across Health, Social Care, Voluntary, Community, Faith sector and CYP organisations within the locality to improve health outcomes for families known to be at risk. Funding: £350k.
- **Oral Health**: a targeted model of oral health education alongside provision of toothbrush packs and supervised toothbrushing with appropriate tools, video links and ongoing parental support. Funding: £274k.
- **Reducing Infant Mortality**: a Trauma Informed Safer Sleep project aimed at reducing infant mortality due to Sudden Infant Death Syndrome by addressing unsafe sleep practices through a trauma-informed lens. Funding: £88k.

Resource funded within system:

- Early years health workforce
- Project manager / project support
- Clinical oversight / Paediatric specialist support in community

Data and Metrics

- Emergency admissions data for early years
- Emergency Department attendance data for early years
- Local - infant mortality data, population health management data, deep dives, health profiles to reduce existing or predicted health inequalities

Resources

- NHS Long Term Plan, NHS 10 Year Health Plan (Spring 2025)
- NHS England » Neighbourhood health guidelines 2025/26
- NHS England » Guidance on neighbourhood multidisciplinary teams for children and young people

- Prioritising early childhood to promote the nation’s health, wellbeing and prosperity The Academy of Medical Sciences (2024)

Mental Health Champions

Case for Change

While most children and young people with mental health needs will receive care and support in community settings, there are occasions where attendance or admission to a paediatric or adult acute setting may indeed be the best clinically appropriate option. The commitments outlined in the NHS Long Term Plan make clear that achieving parity of esteem – valuing mental health equally with physical health – is a key priority, though there is still some way to go in meeting this challenge. For services to be delivered effectively and for patients to feel supported and staff to feel confident, we need to facilitate better integration of physical and mental health for children and young people.

While areas of excellent practice exist, a recent National Confidential Enquiry into Patient Outcome and Death (NCEPOD) report found that mental health care is not given the same level of importance as physical health care for young people in general hospitals across the UK. Given the increase in number and acuity of mental health problems among children and young people, it is inevitable that paediatricians and nurses will be caring for children and young people with a range of mental health difficulties in their setting. As part of trialling 'what works' for children and young people with mental health needs in acute paediatric settings, some areas have established 'Mental Health Champion' roles to ensure that there is designated time within each provider to facilitate the cultural change required for parity of esteem for mental health in the acute setting and to develop staff and ensure children and young people and their families/carers receive appropriate care.

Short description of pilot programme

NHS England supported regions and systems to establish at least one Mental Health Champion in each provider that admits children and young people. We advised that roles should be held by a senior clinician who can admit children and young people to a paediatric ward, and/or who holds clinical responsibility for children and young people in acute settings, in each provider that admits paediatric patients. This is likely to be a paediatrician, senior paediatric nurse, or senior paediatric allied health professional. We recommended an allocation of 1 PA per week as a minimum.

These roles are not intended to provide a greater share of clinical care but to carve dedicated space for a lead professional to advocate for these children and young people and their families; drive improvements in care; and facilitate join-up across CAMHS, mental health liaison teams, mental health nurses, learning disability and autism services, and other key partners.

Objectives

- Facilitating improvements in joint working across their trust and wider system

- Increasing the confidence of their colleagues in supporting these children and young people and their families/carers, through sourcing, signposting and supporting training and education opportunities, and ensuring clear pathways are in place across teams
- Improving the experience of children and young people and their families/carers

Evidence base

These roles have long been advocated for by NCEPOD, RCPCH and others, and have existing equivalents in other paediatric priority areas, such as the named Safeguarding Lead and Diabetes Clinical Lead. Whilst the development of these roles is in its infancy, we anticipate that widespread benefits would result across the pathway from more collaborative and holistic care, including: staff feeling greater confidence and less burnout (and therefore fewer absences); less distress experienced by children and young people and their families on attendance/admission; fewer admissions; fewer repeat attendances/admissions; and decreased length of stay.

Emerging findings / trends

Feedback and surveys over the pilot period have noted positive impact:

- Confidence of staff to care for children and young people with MH needs in the acute setting
- Partnership working
- Advocacy for children and young people/their families and staff
- Staff engagement
- Training of staff and recognising/utilising transferable skills
- Beginning to address ‘negative culture’ by listening to staff concerns
- Learning from and co-developing services with children and young people

Finance

While we do not wish to limit areas in deciding who to assign to this whole, we recommend it is a senior clinician who can admit children and young people to a paediatric ward, and/or who holds clinical responsibility for children and young people in acute/paediatric settings. This is likely to be a paediatrician/senior paediatric nurse/senior paediatric allied health professional, with an allocation of 1 PA/week minimum.

Resources

RCPCH webpage including a role development overview

Supporting children and young people with mental health needs in acute paediatric settings: A framework for systems

NHS111 Paediatric Clinical Assessment Service (PCAS)

Case for change

The national delivery plan for recovering urgent and emergency care, published in January 2023, highlighted the need to ensure that services reflect the needs of different groups of people, including children and young people. In addition, it set out several CYP-specific commitments, including a commitment to scale up a National NHS111 Paediatric Clinical Assessment Service (PCAS)

"Clinical advice to NHS 111 underpins our plan to assess and direct patients to the most appropriate point of care, whether that be self-care, pharmacy, general practice, advice from a paediatrician, mental health crisis centre, an urgent treatment centre, or another setting…. We will roll out paediatric clinical assessment services to ensure specialist input for children and young people is embedded within 111."

The plan committed to providing increased access to specialist advice, for parents and carers, including support from paediatric clinicians who can help them manage illness at home or decide the best route for their care. With the aim of diverting avoidable and inappropriate attendance at primary care and urgent and emergency care settings.

Short description of pilot programme

Phase 1 - In spring 2020, working closely with the Royal College of Paediatrics and Child Health, the national Children and Young People's Transformation Programme and Integrated Urgent Care teams re-deployed paediatric clinicians who were shielding and/or returning into NHS111 services to assist pandemic response efforts. The data indicated significant positive impact on services and patient experience, including marked reductions in avoidable referrals to other services, including Emergecy Departments.

Phase 2 - Based on data collected as part of the initial scheme, funding was secured to establish a national Paediatric Clinical Assessment Service (PCAS) pilot within NHS111 to formally assess the feasibility and impact of a paediatric CAS. NHS England and IC24 worked together to develop the service's clinical profile and to establish a single national clinical queue, enabling other NHS111 providers to refer relevant cases to PCAS. Phase 2 continued to show significant impact.

Phase 3 – This has involved operating a national queue that moved beyond pilot stage and aimed to optimise the service to provide a strong evidence base for regions/systems and Trusts to develop a service. The optimisation involved 3 key areas:

- **Expand clinical profile to ensure maximum impact and benefit** with a focus on responding to higher acuity calls where the biggest impact of paediatric clinicians could be achieved.
- **Increase call volume and amend operational hours** – National flows demonstrate when the service can have the biggest impact. Operational hours increased to include identified higher volume times during the weekend. See next section for recommended operational hours.
- **Ensure that longitudinal data is collected as part of further analysis** - To enable reporting of the patient's touchpoints with other services vs what the recorded advice and outcome in NHS111 was, providing reassurance that the service results in better patient adherence to the advice provided by NHS111.

Evidence base

Since inception PCAS has:

- Embedded paediatric clinicians within NHS111 Clinical Assessment Service. During 2024, 37,538 calls were responded to by PCAS.
- Only 7,484 (19.9%) referrals to PCAS had the outcome of attend A&E which is 3,666 (10% less) than the wider non-paediatric CAS reviewed patients.
- PCAS also had a 63.5% (23,818) self-care/pharmacy outcome compared to 19.6% (7,601) for non-paediatric CAS.

Data collected so far indicated significant differences between PCAS and non-paediatric CAS disposition breakdowns, with over 58% of all cases responded to by paediatricians classified as self-care versus 22.4% in wider CAS.

An independent patient experience evaluation, led by Picker Institute, showed significant differences between experience of calls by parents/carers that were responded to by PCAS, versus non-paediatric CAS. Across all nine experience-based questions, those respondents who had spoken to a paediatric clinician rated the experience of their NHS111 call significantly better compared to those respondents whose call was managed in non-paediatric CAS. Areas with the biggest discrepancy in responses between PCAS and CAS respondents were around the helpfulness of the advice given, caller involvement in decisions and their inclination to use the helpline service again.

Emerging findings / trends

Clinical profile and acuity levels

The PCAS service currently runs using the following clinical profile. However, this may be tailored to specific population features and services.

Symptom Group (SG)	**Symptom Discriminator (SD)**
Skin, Rash	PC full Primary Care assessment and prescribing capability
Cough	PC full Primary Care assessment and prescribing capability
	PC severe illness assessment capability
Toxic ingestion/inhalation/overdose	AMB severe pain
	AMB toxic ingestion
	ED full ED assessment and management capability
Head, facial or neck injury, blunt	AMB Head injury
	Full ED assessment required
	AMB major head/neck injury
	AMB new/worsening breathlessness
	ED full ED assessment and management capability
Unwell, under 1-year old	ED full ED assessment and management capability
	AMB decreased conscious level
	AMB new/worsening breathlessness
	PC full Primary Care assessment and prescribing capability

Phase 3 of the piloting is looking to increase the number of Urgent Treatment Centre (UTC) type disposals as early data suggests that PCAS may downgrade UTC type disposals at a significantly higher rate than the wider CAS.

In agreement with RCPCH, time spent in NHS111 CAS service contributes to training in emergency medicine/care, expanding the pool of clinicians available to work in PCAS. Piloting to date has also evidenced that clinicians are able to work flexibly in PCAS alongside their existing clinical commitments. This means that a significant cohort of paediatric expertise can be onboarded into a PCAS service without depleting existing services.

A mix of Paediatric Advanced Nurse Practitioners (ANPs) and Consultants/Registrars are needed for coverage of the service, with anticipated split of approx. 70/30. The providers may seek to set a minimum number of sessions per week. Based on the current pilot it is suggested that a minimum of 6 hours (2x shifts) per week, which equates to 1.5 PAs or 0.16 WTE, would sufficiently offset onboarding resources.

Operational hours

PCAS is not envisaged as a 24/7 service, however, operating hours should be be aligned to demand trends. ANPs and Paediatric Consultants/Registrars have notably different preferred shift hours and therefore it is important to have an appropriate skill mix to achieve optimal coverage. ANP's tend to work at end of week and paediatric registrars and consultants tend to work midweek. Paediatric calls to NHS111 peak between 4-10pm and during weekends, with flexible shift arrangements available to clinicians. Local models should base operational hours on regional, system and Trust level data.

Adherence to outcomes

In the patient survey most respondents (87% N=1054) whose call was managed in PCAS said they followed all the advice given by NHS111. A smaller proportion of non-paediatric CAS respondents reported following the advice (62% N=24) with (36% N=14) reporting that they either did not follow it at all, or only partially followed it. However further quantitative data is being validated to ensure that those who initially had a self-care outcome did not return to a UTC setting up to 48 hours after contact. Early emerging data suggests adherence is significantly better with the PCAS vs non-paediatric CAS.

Evaluation, Data and Metrics

To assess the impact of PCAS, the following elements should be considered (see figure x):

- Activity data collected by the NHS111 provider of a paediatric CAS
- Additional data collected through NHS111 Pathways to enable comparison to other NHS111 CAS providers
- Clinical audits to assess quality of care
- Percentage of UTC type disposals for children aged under 16 diverted to more appropriate care settings
- Independent patient experience evaluation
- Experience of clinicians onboarded onto PCAS

The national CYP Programme is keen to hear from regions, systems or Trusts considering implementing a paediatric NHS111 CAS. The team can be contacted on: england.cyptransformation@nhs.net

Resources

NHS England » Expansion of NHS 111 to transform patient access