



#GET-A-HEAD CAMPAIGN

RESEARCH &

POLICY REPORT

2025

Harry's Hydrocephalus
Awareness Trust





A Special Message From The Team

We are a user-led charity called Harry's Hydrocephalus Awareness Trust (known as Harry's HAT). We were established in 2019, by the parents of a little boy (called Harry!) with paediatric hydrocephalus.

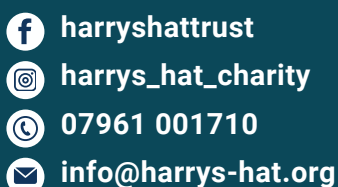
We are experts by experience who live and breathe the impact of paediatric hydrocephalus daily. Last year, over 870 families benefited directly from our work, and over 3000 people were indirectly supported.

Our mission is to make life better for children and their families affected by paediatric hydrocephalus. Hydrocephalus is a potentially life-threatening condition previously known as 'water on the brain'. Every year, around 1 in 770 babies will be diagnosed with the condition.

Hydrocephalus is an abnormal build-up of cerebrospinal fluid (CSF) within the ventricles (cavities) of the brain. The excess CSF causes the ventricles to expand, putting pressure on the brain. Without treatment, the increased pressure can affect development, and in severe cases, lead to permanent brain damage. At Harry's HAT, we work to:

- Raise awareness of the condition
- Provide support to front-line workers so they can improve their knowledge and, consequently, enhance patient care
- Connect families affected by the condition to reduce isolation and build resilience
- Campaign for an early diagnosis for all children

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A National Problem

Where it all started



As a user-led charity, families feel confident to talk to us. Many parents have told us that their child's head circumference was never measured, and/or they had no idea of the importance of routine head circumference measurements, during infancy. Consequently, many parents felt that opportunities to spot their child's hydrocephalus at an earlier stage, had been missed.

Online Survey with Bounty

Routine head circumference measurements are an important indicator of health in childhood, and a relatively cheap, non-invasive, and painless tool for the detection of infantile hydrocephalus. A rapidly growing head is often the first sign of hydrocephalus in babies, so regular measurements of head circumference are crucial for an early diagnosis.

To explore parental knowledge and experiences of routine head circumference monitoring and awareness of hydrocephalus across the UK, we commissioned an online survey with Bounty.

Bounty support UK-based families from pregnancy to pre-school with their free 'Bounty Packs'. Bounty provide expert advice, information, and reassurance, as well as free samples and vouchers.

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Over 750 new parents with babies aged 0-12 months responded to our online survey. It was distributed via Bounty in February-March 2022, via an email mailing list.

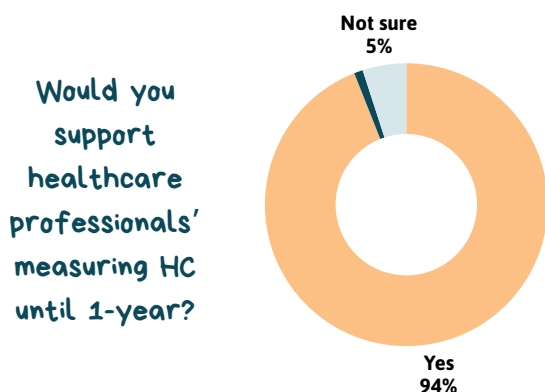
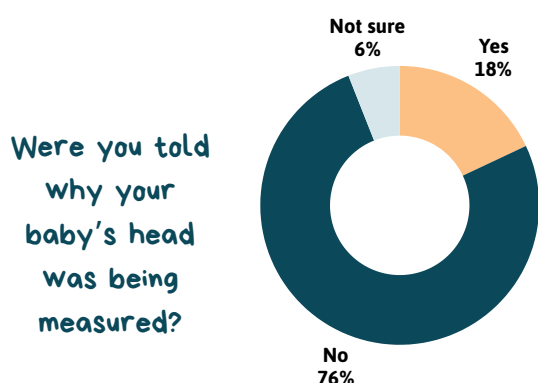
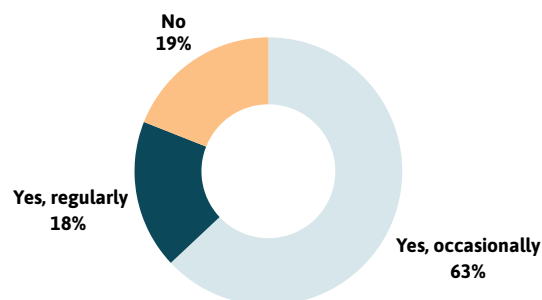


Do you know that your baby's head should be measured at birth?

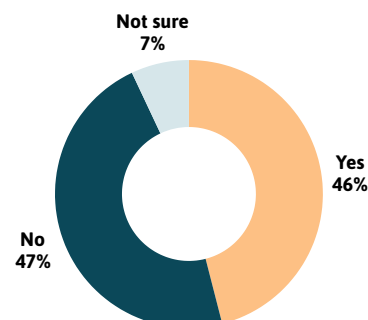


Do you know that your baby's head should be measured at 6-8 weeks?

Did you see your health visitor in person?



Did your health visitor measure your baby's head?



Have you heard of hydrocephalus?



Do you know that measuring a baby's head can help identify hydrocephalus?

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A Targeted Approach



The #GetAHead Campaign

In response to our findings, we launched the #Get-A-Head campaign in 2022. It was originally launched to raise awareness of the importance of head circumference measurements in infancy, and to educate parents on when and why they're taken.

However, it was quickly apparent that the problems facing families and healthcare professionals were far greater than we expected.

As well as a lack of awareness amongst parents as to why routine head circumference measurements are important, and many families missing out on mandatory checks, we found varied and contradictory clinical guidance governing what constitutes abnormal head growth, and when to refer a baby to a specialist.

Phase 2 of the #Get-A-Head campaign is therefore going further with its ambition to revolutionise health care for babies, by asking for improvements in three important areas:

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The Three C's

The #GetAhead Campaign



As a user-led charity, we're campaigning for:

Contact:

Increase the minimum number of **mandatory** face-to-face **contacts** with health professionals who are trained to measure head circumference and interpret the result, in the first year of a child's life. For example, health visiting teams in Scotland carry out eight visits with a family in the first 12 months. In England, families are offered just two visits in the first 12 months of life.

Communication:

Midwives, GPs, and health visitors should explain **why** they perform each one of their checks, to parents and carers. For example, does the parent know why head circumference measurement is important? And do they know when to expect this measurement to be taken again?

Concern:

A **review** of the current **clinical guidelines** from NICE and the RCPCH which outline when and how a health professional should refer a child with concerning symptoms to a specialist team, regardless of postcode.

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Open Letter and Petition



The #GetAHead Campaign

To raise awareness and garner support, we submitted an open letter to the Health Secretary, and launched a public petition. Support amongst healthcare professionals, the public and central government for the #Get-A-Head campaign is critical.

Open letter to the Health Secretary:

Every paediatric neurosurgical centre across the UK signed our open letter to the Health Secretary, calling for a review of the current guidelines on routine head circumference monitoring during infancy. Find out more about our open letter at: harrys-hat.org/get-a-head/openletter

Public petition:

We also launched a public petition, which has amassed over 25,000 signatures. There is still time to add your voice, so please visit our petition and add your name at: www.change.org/measurebabyheads

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Support from the Health Secretary



The #GetAHead Campaign

Meeting with the Health Secretary, Wes Streeting MP

We are passionate about calling for change, and recently met with the Health Secretary Wes Streeting MP, and the Speaker of the House, Sir Lindsay Hoyle MP, to discuss the #Get-A-Head campaign.

On Wednesday 13th of November Wes Streeting MP publicly committed his support. He thanked us for the campaign, and stated on record that all babies deserve the best start in life.

His office will consult with NICE and the Royal College of Child Health and Paediatrics (RCPCH) on whether a review of the current clinical guidelines should be commissioned.

We look forward to hearing more in due course and want to thank Wes Streeting MP and Sir Lindsay Hoyle MP, and all our supporters, for their help with the Get-A-Head campaign!

Thank you!

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SECTION 1:

NATIONAL POLICY ON THE TIMING OF UNIVERSAL HEALTH AND WELLBEING REVIEWS DURING INFANCY

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The Healthy Child Programme



Universal Health Reviews

Timing of universal health reviews during infancy

In England, the Healthy Child Programme (introduced in 2009 and updated in 2023) sets out a timeline of health and well-being reviews, during infancy and early childhood (1,2). Each UK nation has different schedules and policies for delivering child health programmes (3).

As part of the Healthy Child Programme in England, local authorities are legally obliged to offer parents **three** health and wellbeing reviews during infancy, irrespective of whether it's their first child or not (1). These mandatory visits should be conducted face-to-face by a health visitor (or GP for the 6-8-week review), and should occur:

- at around 10-14 days (the new baby review)
- at 6 to 8 weeks
- at 1 year

Additional contacts can be offered at 3 and 6 months if a need has been identified by the health visitor. These are not mandatory.

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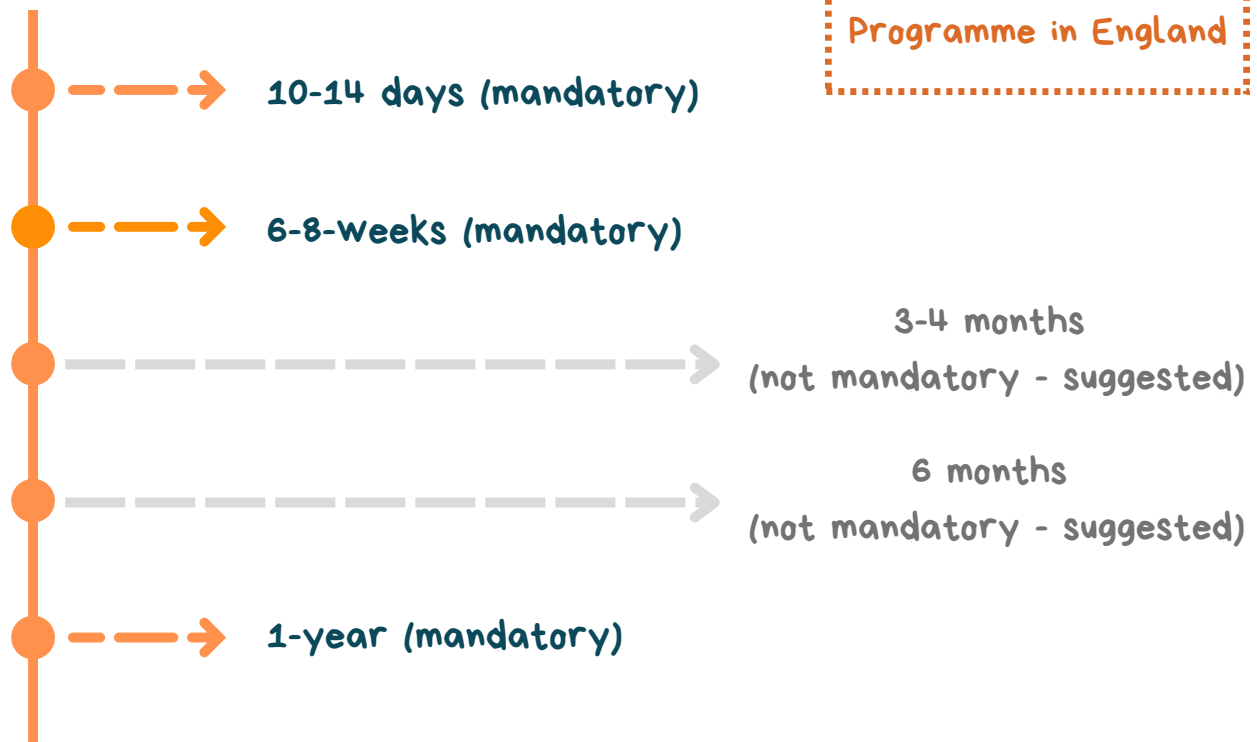
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The Healthy Child Programme



Universal Health Reviews

Timing of universal health reviews during infancy



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The Healthy Child Programme



Universal Health Reviews

Data and evidence review: areas of concern

1. Not all infants receive their mandatory universal reviews

The Office for Health Improvement and Disparities (OHID; formerly Public Health England) publish quarterly data from each local authority in England on the percentage of mandatory reviews that are completed (4). For example, the following data is published for reviews carried out during infancy:

- percentage of births that receive a new birth visit within 14 days
- percentage of births that receive a new birth visit after 14 days
- percentage of infants that received a 6-8-week review by 8 weeks
- percentage of infants who received 12 month review by 12 months
- percentage of infants who received 12 month review by 15 months

Data from OHID [Figure 1] reveals that in 2021-2022 (quarter 1), 85% of infants received their newborn home visit within 14 days, and 84% of infants received their 6-8-week check by 8 weeks (4).

It's not possible to determine **why** a significant proportion of infants are missing their universal reviews (e.g. the contact wasn't offered or they did not attend), as this data is not available as part of the national audit (5).

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The Healthy Child Programme

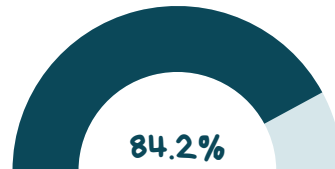


Universal Health Reviews

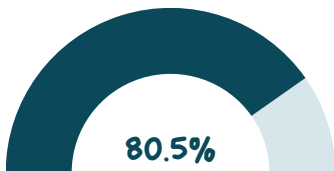
Figure 1: health visitor service delivery data from OHID (4) for 2021-2022 (quarter 1)



percentage of births that receive a new birth visit within 14 days



percentage of infants that received a 6-8-week review by 8 weeks



percentage of infants who received 12 month review by 12 months



Percentage of children who received a 2-2.5 year review

Percentage of babies that had the 6-8-week visit by 8 weeks: best and worst areas in England



Sandwell, West Midlands



Bedford, East of England

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The Healthy Child Programme



Universal Health Reviews

Data and evidence review: areas of concern

2. Disparities in the universal offer across the United Kingdom

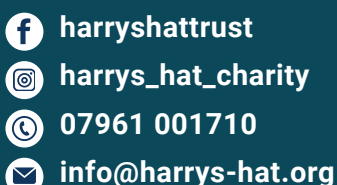
In Scotland [see Table 1] all infants are offered **seven** contacts during infancy as part of the universal health visiting pathway, which is more than double the number of contacts offered in England (1,6). In Wales, **six** contacts are offered to all infants (7).

3. Demographic and geographical disparities across England

According to data published by OHID (4) there are significant disparities between local authorities in England, in terms of the percentage of universal visits that are completed [Figure 1]. For example, the percentage of infants who received the 6-8-week check by 8 weeks in the best and worst performing areas was 99.9% and 4%, respectively.

There is also evidence to suggest that infants in disadvantaged areas of England are less likely to receive their universal checks during the first year of life. Worryingly, the variation in the completion of checks during infancy also depends on ethnicity (8).

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The Healthy Child Programme



Universal Health Reviews

Table 1. Comparison across England, Scotland and Wales

Country	Timing of universal reviews during infancy	Notes
The Healthy Child Programme, England, 2023 (1)	Three contacts during infancy: • 10-14 days home visit • 6-8-week health visitor/GP visit • 1-year home visit	Additional contacts can be offered at 3 and 6 months if required
Universal Health Visiting Pathway Scotland, 2015 (5)	Seven contacts during infancy: • 11-14 day home visit • 3-5 weeks: x2 home visits • 6-8- week home visit • 3 months home visit • 4 months home visit • 6 months home visit • 8 months home visit	
Healthy Child Wales Programme, 2016 (6)	Six contacts during infancy: • 10-14 days home visit • 6-8 weeks GP contact • 8 weeks clinic contact • 12 weeks clinic contact • 16 weeks clinic contact • 6 months home visit	Additional health visitor contact can be offered at 6 weeks if needed

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The Healthy Child Programme



Universal Health Reviews

Data and evidence review: areas of concern

4. In-depth data from each universal review are not audited

Whilst data on the number of reviews that are completed is published by OHID (4), there is no data on what checks were carried out during each review, and whether any abnormalities were found, or referrals made. This makes it difficult to monitor the success of the programme in terms of identifying concerns early.

Furthermore, as virtual checks are included in the OHID audit in some locations in England, the usefulness of this data is unclear (5).

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Universal Health Reviews

Table 2. Summary of areas of concern and potential solutions

Area of concern	Potential solution
Not all infants receive their mandatory reviews	Mandatory recording of reason for missed checks could be introduced and included in the OHID audit.
There are disparities in the Universal offer across the United Kingdom	In Wales, health-visitor led growth monitoring checks are combined with the routine vaccine schedule at 8, 12 and 16 weeks (7). During infancy, routine vaccinations in England are carried out at 8, 12 and 16 weeks, and 1 year (9). Additional universal reviews could be conducted at these pre-existing appointments without the need for additional checks in the universal offer.
Demographic and geographic disparities across England	Targeted awareness programmes with families, community health teams, and GPs in regions where completion of mandatory contacts is low.
In-depth data from each universal review is not audited	Digitisation of the Personal Child Health Record or 'Red Book' may provide a more efficient method of recording and analysing routine population-based data already captured during universal reviews. This data could be nationally audited, and would improve routine health monitoring during childhood.

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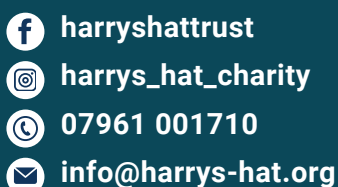


Universal Health Reviews

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SECTION 2:

NATIONAL POLICY ON WHEN HEAD CIRCUMFERENCE SHOULD BE MEASURED

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Head Circumference Measurement



National Guidance

Timing of routine HC measurements during infancy

National guidance on when routine head circumference (HC) measurements should be conducted during infancy is available from a number of sources [see Table 1] including the Healthy Child Programme (1), NICE guidelines on Postnatal Care (2), and the Royal College of Paediatrics and Child Health (3,4).

While the number of universal health reviews offered during infancy varies significantly between England (1), Scotland (5) and Wales (6), the number of routine HC measurements does not [see Table 2].

Typically, HC is measured around birth (once cranial moulding has resolved) and at the 6-8-week review (1,5,6). The Healthy Child Wales Programme also recommends a routine measurement at the 2-week (new baby) review (6).

Across the UK, additional HC measurements are only recommended if concerns are identified by the parent, or healthcare professional (1,5,6).

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Head Circumference Measurement



National Guidance

Table 1. National guidance on routine head circumference monitoring

Guideline	Target Audience	Recommendations
The Healthy Child Programme, England, OHID, DoH. 2023 (1)	Local authorities, the NHS and other partners, in England	• 6-8-week visit
NICE Guideline: Postnatal Care [NG194]. Updated 2023 (2)	Healthcare professionals, Commissioners and providers, Women having routine postnatal care, and their families, in England	• in the first week • around 8 weeks • at other times if there are concerns
Royal College of Paediatrics and Child Health (3,4)	Healthcare professionals in the UK	• around birth (once moulding has resolved) • 6-8-week visit • if there are concerns about the child's head growth or development

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Head Circumference Measurement

National Guidance



Table 2: Policy comparison across England, Scotland, and Wales

Programme	Timing of universal contacts during infancy	Timing of head circumference measurements
The Healthy Child Programme, England, 2023 (1)	• 10-14 days home visit • 6-8-week health visitor/GP visit • 1-year home visit	• birth • 6-8-weeks
Universal Health Visiting Pathway Scotland, 2015 (5)	• 11-14 day home visit • 3-5 weeks: x2 home visits • 6-8- week home visit & GP contact • 3 months home visit • 4 months home visit • 6 months home visit • 8 months home visit	• birth • 6-8-weeks
Healthy Child Wales Programme, 2016 (6)	• 10-14 days home visit • 6-8 weeks GP contact • 8 weeks clinic contact • 12 weeks clinic contact • 16 weeks clinic contact • 6 months home visit	• birth • 10-14 days • 6-8-weeks

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Head Circumference Measurement



National Guidance

Data and evidence review: areas of concern

1. Routine monitoring of head circumference stops at 8 weeks of age across the UK

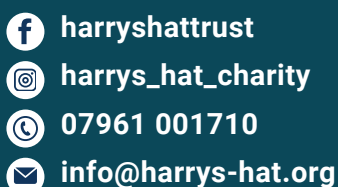
The latest guidance across the UK recommends routine HC measurements around birth, and at the 6-8-week check, but not beyond unless concerns are identified (3,4-6). According to the guidance, there is no evidence to support routine HC monitoring after 8 weeks of age (3). One study (below) was cited to support this approach:

Wright & Emond, 2015: data from a UK population-based study in Avon (7)

Wright and Emond retrospectively reviewed data from The Avon Longitudinal Study of Parents and Children (ALSPAC) of 14,701 children, to establish the value of HC as a screening test.

HC was measured routinely by local health services at 2, 9 and 18 or 24 months. A subgroup of children also had their HC measured by research staff at 4, 8, 12 and 18 months. The incidence of centile shifting and extreme head size was calculated using both internally standardised z scores and the WHO growth standard. Data on IQ according to the Wechsler Intelligence Scale for Children and neurocognitive disorders were linked with head circumference data.

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Head Circumference Measurement

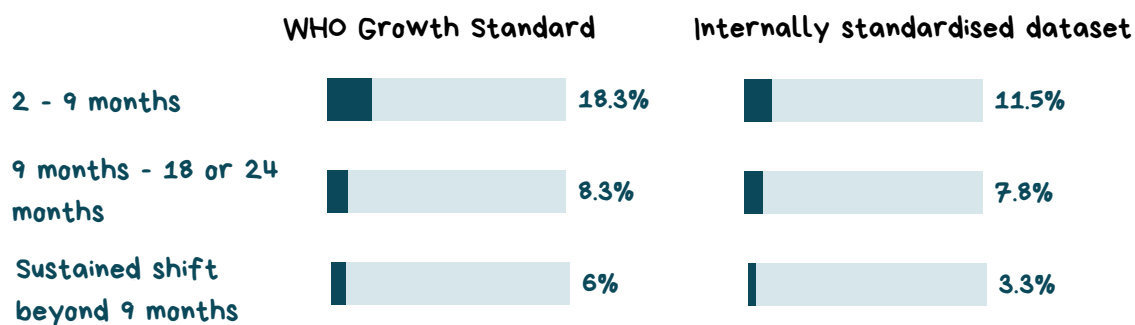
National Guidance



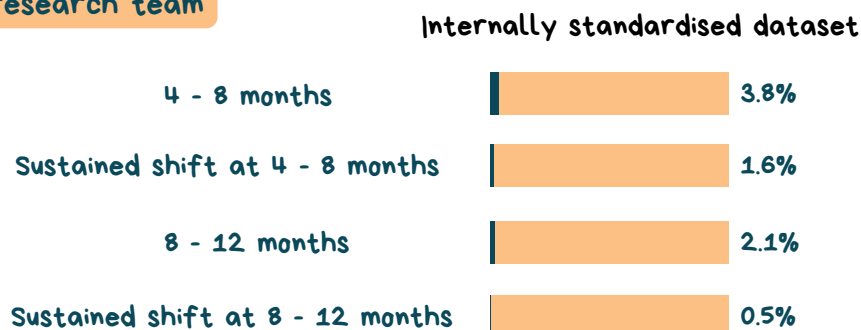
Data and evidence review: areas of concern

Wright & Emond, 2015 (7): pertinent findings

% of children with upwards centile crossing (+2 z) when HC measured (routinely) by community health team



% of children with upwards centile crossing (+2 z) when HC measured by the research team



Centile crossing is more common when using the WHO Growth Standard, rather than local reference data for HC

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Head Circumference Measurement



National Guidance

Data and evidence review: areas of concern

Wright & Emond, 2015 (7): pertinent findings cont.

Upwards centile crossing

- Centile crossing was common, occurring in 12-18% of children depending on the chart the data were plotted on
- By using the WHO growth standard (rather than internally standardised data), centile shifts were more common
- Centile shifts were less common when HC measurements were performed by researchers
- Centile shifting was more common in the first 8-9 months of life
- Most centile shifts were not sustained, occurred within the normal range, and likely reflected measurement errors
- Centile shifts out of the normal range were more rare

HC measurements

- There was a high degree of 'within subject' variability with routinely recorded HC measurements

Neurocognitive disorders and HC

- Extremes in head size are not a good predictor of later neurocognitive disorders

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Head Circumference Measurement



National Guidance

Data and evidence review: areas of concern

Wright & Emond, 2015 (7): conclusions

The authors concluded that because centile shifts were so common using the WHO growth standard, centile shifting often reflected measurement error, and HC isn't a good predictor of later neurocognitive disorders:

- HC should be measured routinely around birth (once cranial moulding has resolved), and once more before 6 months, but not otherwise
- More frequent measurements will lead to more 'spurious' results, unnecessary referrals, scans, and parental anxiety
- Repeated measurements should only be taken when early measurements are extreme i.e. outside +2 standard deviations

Wright & Emond 2015: Our concerns

- The purpose of routine HC monitoring is to identify abnormal patterns of growth, including intracranial expansive conditions such as hydrocephalus, and not to identify neurocognitive disorders
- Rapid head growth is more common in the first 6-10 months of life (7-9), so routine monitoring should extend throughout this period

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Head Circumference Measurement



National Guidance

Data and evidence review: areas of concern

Wright & Emond 2015: Our concerns cont.

- There is no evidence to suggest monitoring after 8 weeks is not useful - indeed, the majority of infants with hydrocephalus & rapid head growth will present in the first 2-10 months of life (8)
- Many infants with hydrocephalus will have rapid head growth and a HC within the normal range (8). Only re-measuring infants with extreme HC values, as the authors propose, would lead to a late diagnosis in these infants
- The evidence clearly suggests that UK babies' heads appear larger when compared to the WHO growth standard, rather than local reference data (7,9). The rate of apparent centile crossing also increases when using the WHO Growth Standard (7,9).
- This is a significant concern, and as a result, the authors previously predicted that using the UK-WHO growth charts would lead to an increase in the number of babies referred with rapid head growth for further testing, unnecessarily (7,9), other symptoms and signs would become more important, and regular HC measurements would be unhelpful (7,9)
- However, as the authors state in the current study, there is no evidence to suggest there was an increase in unnecessary referrals (7), so adjusting national policy preemptively on this basis, may have had no benefit

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Head Circumference Measurement



National Guidance

Data and evidence review: areas of concern

2. The ideal duration and timing of routine head circumference measurements is unclear

The ideal timing of routine head circumference measurements in order to detect hydrocephalus early, is a point of contention.

Based on their findings, Wright and Emond recommended a routine HC measurement in the first 2-5 days after birth (after cranial moulding has resolved), and once more before 6 months of age (7). Otherwise they do not recommend routine HC monitoring.

However, the focus of their study was whether or not HC could be used to predict later neurocognitive disorders, and not on how to optimise detection of infantile hydrocephalus.

Firstly, it's important to define the time period across which routine HC measurements would be beneficial in order to capture most cases of hydrocephalus, specifically. This is called the 'critical period'.

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Head Circumference Measurement



National Guidance

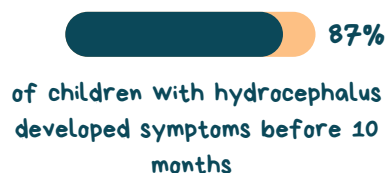
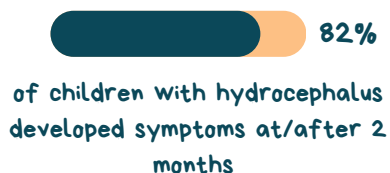
Data and evidence review: areas of concern

How long should routine HC monitoring last: defining the 'critical period'

The most accurate way of detecting hydrocephalus early in infants without known risk factors, is a rapidly growing HC (8). Furthermore, infants without any HC measurements during the first year of life are more likely to be referred with neurological abnormalities, than infants with HC measurements (10).

Research suggests that the majority of centile crossing will occur within the first 6-9 months of life (7,9). From what little data is available on the presentation of infantile hydrocephalus specifically, we know that the majority of cases present with a rapidly growing head within the first 10 months of life (8), specifically between 2 and 7.5 months of life, with a mean age of symptom onset of 4.8 months (median 4 months; range 0-27 months).

The critical time period would therefore appear to be the first 10 months of life, with the peak of cases expected between 2-7.5 months (8).



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Head Circumference Measurement



National Guidance

Data and evidence review: areas of concern

When should routine measurements of HC be performed during the 'critical period'

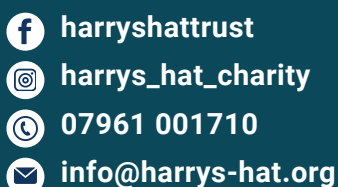
The only available research study that has closely examined the timing of symptom onset in infantile hydrocephalus is from Zahl and Wester 2008 (8). The authors' findings may be useful to policy makers when trying to establish the ideal timing of routine HC measurements, in order to optimise detection of infantile hydrocephalus, specifically:

Zahl and Wester, 2008: A Norwegian population-based study (8)

The authors retrospectively examined records of all children aged 0-5 years who were diagnosed with an intracranial expansive condition and required hospitalisation, in Norway.

National guidelines require any child with a head circumference that has crossed 2 or more centile lines (based on local reference data), to be referred to a specialist. Where a diagnosis of hydrocephalus was expected (e.g. myelomeningocele), the child was excluded from the study.

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Head Circumference Measurement



National Guidance

Data and evidence review: areas of concern

Zahl and Wester, 2008: A Norwegian population-based study (8)

Of the infants with hydrocephalus who were referred before 12 months of age on the basis of rapid head growth, the authors' data suggest:

A head circumference measurement at around 2-3.5 months of age would detect

39% of cases

A head circumference measurement at around 4-5.5 months of age would detect

66% of cases

A head circumference measurement at around 6-7.5 months of age would detect

91% of cases

A head circumference measurement at around 8-9.5 months of age would detect

99% of cases

There is evidence to support continuing routine monitoring beyond 8 weeks of age.

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Head Circumference Measurement



National Guidance

Data and evidence review: areas of concern

Zahl and Wester, 2008 (8): Our concerns

- Research shows that the rate of apparent centile crossing is different, depending on the growth chart used to plot a baby's data (5,7). In their study, Zahl and Wester used local growth charts to plot head circumference data. It's unclear whether the timing and presentation of symptoms would be comparable when plotting UK-based infants data on the UK-WHO growth charts.
- Unfortunately, There are no UK studies (carried out using the UK-WHO growth charts) that have examined the type and timing of symptoms of infantile hydrocephalus, including rapid head growth. Establishing what symptoms appear and when, including the onset of rapid head growth, would provide guidance as to when routine head circumference measurements should be carried out, in order to optimise detection of hydrocephalus.

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Head Circumference Measurement



National Guidance

Data and evidence review: areas of concern

3. The UK lags behind many other European countries with respect to routine HC monitoring in infancy

Interestingly, infants across the UK currently receive far fewer routine HC measurements than infants born in other European countries. For example, a baby born in the UK will typically receive two routine HC measurements during infancy (1), whereas a baby born in Finland or Norway will receive 10 and 11 measurements, respectively (11).

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Head Circumference Measurement



National Guidance

Table 3. Summary of areas of concern and potential solutions

Area of concern	Potential solution
Routine monitoring of HC stops at 8 weeks of age in the UK	Research shows the majority of infants with rapid head growth and hydrocephalus develop symptoms between 2-10 months of age (8). Extend routine HC monitoring by combining pre-existing routine vaccination appointments at 12 and 16 weeks with growth monitoring (including HC), as is standard practice in Wales (6). Review evidence to determine whether it is strong enough to warrant additional reviews.
The ideal duration and timing of routine head circumference measurements is unclear	Research suggests that additional routine HC measurements at around 4-5.5 months, 6-7.5 months and 8-9.5 months would capture 66%, 91% and 99% of infantile hydrocephalus cases referred on the basis of rapid head growth, respectively (8). Consider introducing additional checks at around 4 and 6 months, utilising pre-existing routine appointments where possible.. Conduct a population-based study across the UK with the BPNG, to identify when, how and where infants with hydrocephalus initially present.
The UK lag behind many other European countries with respect to routine HC monitoring during infancy	Form a national coalition of charities and patient support groups who support children with conditions other than hydrocephalus, that may also benefit from increased routine HC monitoring e.g. craniosynostosis, microcephaly. Re-submit a joint proposal to the National Screening Committee, and RCPCH, on changing UK policy.

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Head Circumference Measurements



National Guidance

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SECTION 3:

NATIONAL POLICY ON WHAT TO DO IF A CONCERN IS IDENTIFIED DURING ROUTINE SCREENING

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Recognition and Referral



National Guidance

Recognising infantile hydrocephalus in the community: what is abnormal?

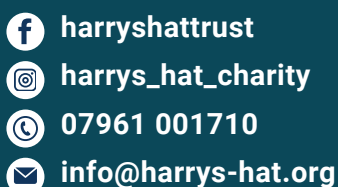
There are currently no national guidelines on the recognition and referral of infantile hydrocephalus, specifically. The latest guidance on what constitutes abnormal head growth, and other pertinent symptoms and signs (relating primarily to raised ICP), is available from the RCPCH (1) and a generic NICE guideline (2) on recognition and referral of neurological conditions (see Table 1).

Infants with hydrocephalus will typically present with rapid head growth, with or without macrocephaly, particularly in the first 10 months of life (3). Importantly, a significant proportion of infants with rapid head growth will have a HC centile within the normal range (3), so routine HC monitoring is critical.

Classical symptoms and signs of hydrocephalus or raised intracranial pressure (ICP) such as vomiting, a bulging fontanelle, and visual disturbances, may be present, but typically occur later (3).

Standard practice in the UK has been to define rapid head growth requiring further assessment as a HC that has crossed through two or more centile lines, on an age- and sex-standardised growth chart (4). Macrocephaly is defined as a HC greater than 2 standard deviations above the mean for age and sex (5).

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Recognition and Referral

National Guidance

Table 1. Current guidance across the UK

Guidance	Symptoms	Management
RCPCH Guidelines (1)	HC crossed 2 or more centile lines OR is above the 99.6th centile	Re-measure in 1-3 months - if the head centile is still rising, they should be referred to secondary care - If it is stable or falling, no further action is required
	HC crossed 2 or more centile lines or is above the 99.6th centile AND any neurological symptoms	Refer <u>urgently</u> for assessment in secondary care.
NICE Guidelines (2)	HC crossed 2 or more centile lines OR is above the 99.6th centile	Routine referral to paediatric services for assessment and cranial imaging to exclude progressive hydrocephalus.
	HC above the 98th centile without centile crossing/other concerning symptoms or signs	Note the head size of the biological parents, if possible, to check for familial macrocephaly If familial macrocephaly likely, do not routinely refer the child in the absence of any other problem
	HC crossed 2 or more centile lines AND tense fontanelle, sixth nerve palsy, sunsetting, vomiting, unsteadiness, or headache.	Refer <u>immediately</u> to paediatric services for same day assessment

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Recognition and Referral



National Guidance

Data and evidence review: areas of concern

1. There is discordance across RCPCH and NICE guidelines on what constitutes abnormal growth, or warrants specialist referral

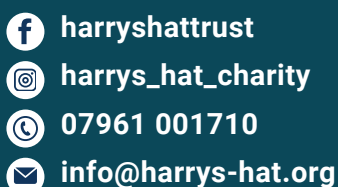
According to current NICE guidelines (2), a child with a HC that has crossed 2 or more centile lines requires a referral to paediatric services, to exclude hydrocephalus. This applies even in the absence of other classical symptoms and signs of raised ICP/hydrocephalus.

In contrast, current advice from the RCPCH (1) recommends re-measuring the HC in 1-3 months in the first instance, and only then, referring to secondary care if it is still rising.

To further complicate matters, the RCPCH provide additional and conflicting advice on their website (6), and on the current UK-WHO growth charts (7), stating:

"..A head circumference above the 99.6th centile, or crossing upwards through 2 centile spaces, should only cause concern if there is a continued rise after 6 months, or other signs or symptoms."

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Recognition and Referral



National Guidance

Data and evidence review: areas of concern

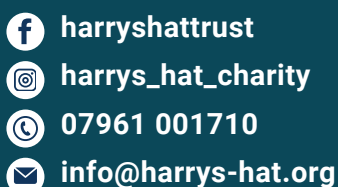
Both guidelines, however, are in agreement that if a child has a rapidly growing head and additional neurological signs, they require urgent or immediate referral to secondary care (1,2).

However, the differences both across and within NICE and RCPCH recommendations with regards to a child with a rapidly growing head, a key sign of infantile hydrocephalus, and sometimes the only presenting sign (3), is concerning, and poses a significant challenge for healthcare workers who identify these signs in clinical practice.

2. The guidance available from the RCPCH varies, depending on the resource used

As previously stated, the guidance from the RCPCH as to the significance of a centile shift upwards of 2 or more centiles differs, depending on the resource used (1,4,6,7). Previous guidance from the RCPCH in 2009 stated that fewer than 1% of infants will cross 2 or more centile lines (up or down), so this degree of centile shift warrants careful assessment (4). This guidance is still available on

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Recognition and Referral



National Guidance

Data and evidence review: areas of concern

the RCPCH website. More recent advice states that a child with this degree of centile shift either:

- requires re-measuring in 1-3 months (1) or
- that it is not a significant concern unless it continues past 6 months, OR they present with additional symptoms or signs (6,7).

The conflicting advice as to the significance of centile crossing may have arisen as a result of the introduction of the UK-WHO charts in the UK in 2009, where it has since been established that:

- UK babies appear larger than the WHO standard, and upwards crossing of 2 or more centiles and a HC >98th centile would become more common (8,9)
- Centile crossing is less common after 6 months of age (8)

It was concluded that extreme values of HC and other symptoms/signs would thus become more important, in terms of screening for hydrocephalus (8,9).

Nevertheless, given the median symptom onset for children with hydrocephalus and rapid head growth is 4 months (3), advice stating that it only becomes an issue after 6 months, is concerning.

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Data and evidence review: areas of concern

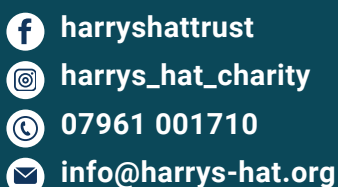
3. NICE guideline [NG127] was previously revised due to inappropriate recommendations

The NICE guideline for Recognition and Referral of Neurological Conditions (2) was launched in 2019 and was subsequently revised. It initially stated that a child with a rapidly growing HC and symptoms and signs of raised ICP required an urgent (within 2 weeks) appointment. This was revised to 'immediate' or same-day appointment, following concerns raised.

Contained within the same guideline (2) is advice that a child with a rapidly growing head (without additional symptoms and signs of raised ICP), requires a 'Routine' referral to rule out hydrocephalus.

Given most infants with hydrocephalus present with a rapidly growing head initially (3), and the term 'Routine' is not defined in terms of a timeframe, it's unclear whether this advice is sufficient, or requires further examination.

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National Guidance

Data and evidence review: areas of concern

4. Current guidance is not geared towards early detection of infantile hydrocephalus

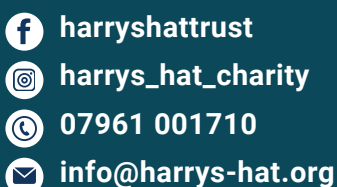
As previously stated, both NICE and the RCPCH are in agreement that a child with a rapidly growing (or large) head and additional signs of raised ICP, requires an immediate/urgent referral to secondary care (1,2).

However, some of the additional symptoms and signs listed by NICE as essential in order to make an urgent referral, are rare in children with hydrocephalus who present in the first 10 months of life (3).

Whereas an increasing HC was seen in 72% of 216 children with hydrocephalus at the time of symptom onset, visual disturbances were seen in 1%, a bulging fontanelle in 3%, and unsteadiness in 2%. Symptoms such as nausea/vomiting were seen in 9%, whining/irritability 8% and aberrant head shape in 6%, so were slightly more common (3).

Furthermore, separate and conflicting advice from the RCPCH stating that a child with rapid head growth requires re-measuring in 1-3 months (1), or that centile crossing only poses a concern if it continues after 6 months (6,7) may not facilitate an early diagnosis given median symptom onset is 4 months (3).

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Recognition and Referral

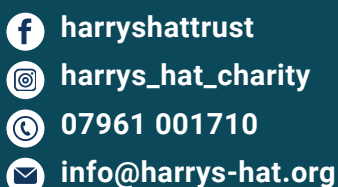


National Guidance

Table 2. Summary of areas of concern and potential solutions

Area of concern	Potential solution
There is discordance across national guidelines on what constitutes abnormal growth or warrants specialist referral	Clarification for healthcare professionals on what constitutes abnormal growth or warrants a specialist referral, is critical. Development of a hydrocephalus-specific guideline, inclusive of all relevant specialties (e.g. neurosurgery, paediatrics, GP, neuroradiology) may help to build a consensus.
The guidance available from the RCPCH varies, depending on the resource used	Liaise with RCPCH regarding conflicting advice, and potential confusion it may cause for healthcare professionals, and families.
NICE guideline [NG127] was previously revised due to inappropriate recommendations	Liaise with NICE as to the exact definition of a 'Routine Referral', and with the BPNG as to whether this timeline is appropriate to rule out hydrocephalus in a child with rapid head growth.
Current guidance is not geared towards early detection of infantile hydrocephalus	A prospective population-based study conducted with the BPNG on the presentation of infantile hydrocephalus across the UK might help to define best practice and optimise early detection.

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Recognition and Referral



National Guidance

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