



# ANTENATAL SCREENING IN RELATION TO HYDROCEPHALUS



Community  
Research Hub

With thanks to students at the Royal  
Holloway University Community  
Research Initiative for their survey input



# Study Overview and Objectives

This piece of research was conducted by a charity called Harry's Hydrocephalus Awareness Trust (Harry's HAT), which is the only UK charity to focus solely on hydrocephalus.

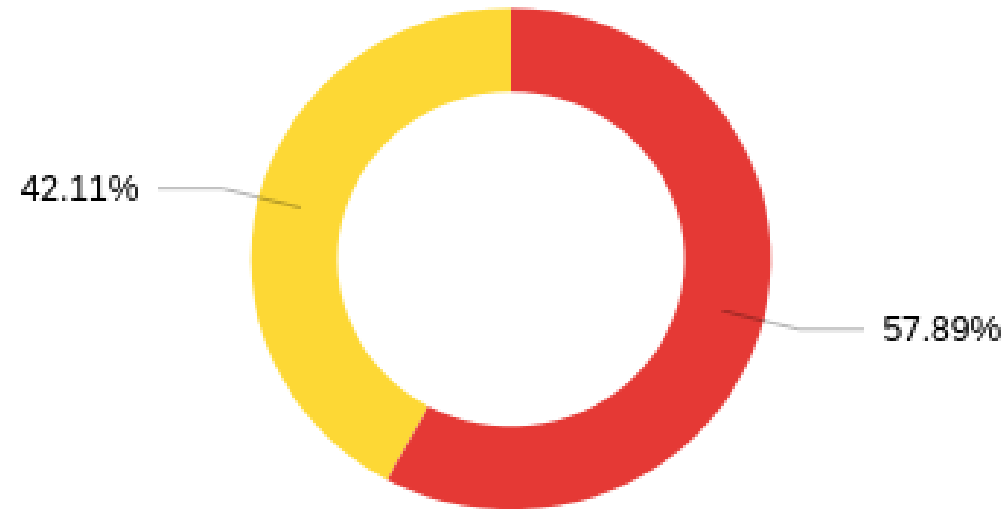
The overall aim of the charity is to improve life and outcomes for children with hydrocephalus and for those who love and care for them.

This research focused on your experiences of:

- Antenatal care and the impact of third trimester screening on the outcome for babies born with hydrocephalus.
- When you received a diagnosis and its impact on health outcomes and your experiences.
- The information and support that you received at the time of diagnosis.



## Did you receive a 3rd trimester screen?



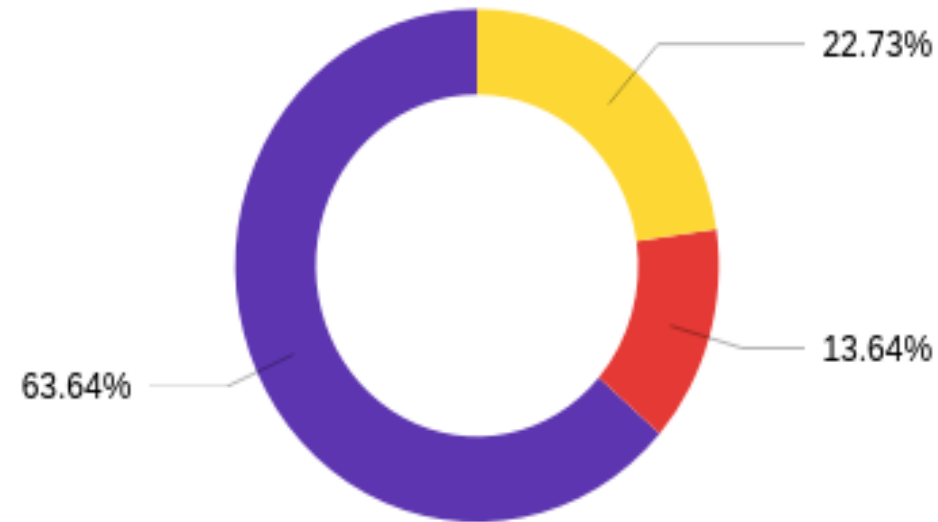
Yes, it was offered to me on the NHS    Yes, it was offered to me privately

Yes, I asked for it on the NHS    Yes, I asked for it privately    No, it was not offered to me

No, it was offered but was too expensive    No, it was offered to me but I wasn't interested



We asked about the 3rd trimester screening information you received during pregnancy



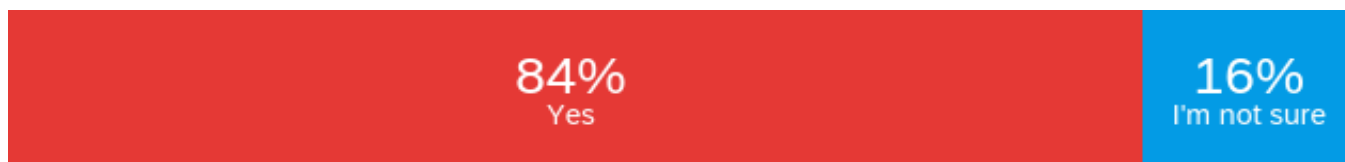


Knowing what you do now, we asked for your thoughts and feelings on 3rd trimester antenatal Screening

Would you like to have received more screening information?



Would you like to have been offered a 3rd trimester scan?

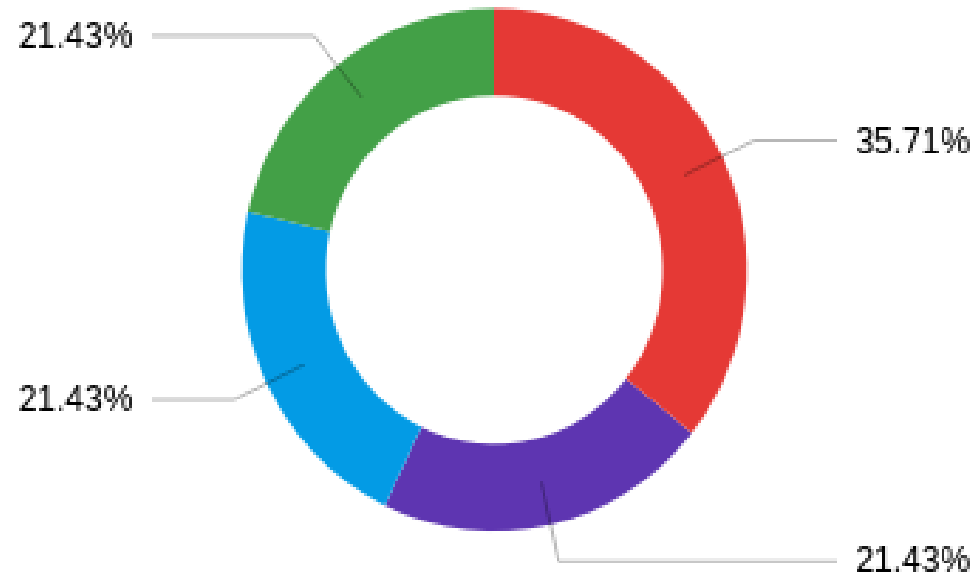


Would you have been willing to pay for a 3rd trimester scan?





## We asked about when your child was diagnosed



■ My child's hydrocephalus was detected during a routine scan

■ My child's hydrocephalus was detected during a routine health check up

■ My child's hydrocephalus was diagnosed quickly once they showed symptoms related to it

■ My child's hydrocephalus was only diagnosed following many tests for unexplained symptoms



# We asked if you believed that the stage at which diagnosis was made affected your experiences

"Yes, she has brain damage because it was left undiagnosed for so long."

"I feel sooner intervention should have been carried out. I knew he was developmentally delayed and I believe he began developing when he had his shunt. I am very angry with the system for letting us down. I had regular scans due to his head size, he was in NICU for a week postnatally, we were in and out of hospital every week till diagnosis, health visitors didn't visit. So so many potential times to diagnose."

"If my son was diagnosed during pregnancy scans then he would not have had increased pressure for 9 months. He now has a shunt anyways but we also don't know what that he was brain damaged because of the increased pressure."

"I think it helped that they found out before it started that there was something wrong so she was continually monitored and everything was done quickly."

"Yes, my son was extremely unwell & it was brushed under the carpet time after time. He had every sign and symptom of hydrocephalus. I was then referred to see someone as the Drs thought I had some form of post natal psychosis! This wasn't the case and my son needed emergency surgery something they weren't sure would work thankfully it did but it truly affected my trust in Drs"

"My child was not diagnosed until 8 months old, the news came as a big shock and was very traumatic as surgery was needed immediately. A scan in the third trimester may have detected her dandy walker syndrome and her hydrocephalus may not have become so severe before being picked up. Now she has developmental delays that might have been avoided."



## We asked about the support you received at the time of diagnosis

"Clinical specialist at kings is very helpful. Surgeon and his fellow always supportive and answer our questions."

"Pretty much none! Was diagnosed one day, shunt placed the next!"

"Very little from my local hospital. I was alone in the room with him and a Dr and nurse. My husband wasn't allowed in. We were all wearing masks. I wasn't even hugged because of COVID. Shine have been amazing!!!  
As were Sheffield Children's hospital"

"Absolutely none"

"Doctors explained things but we weren't given any information about support groups or help out there such as charities etc."

"I received great support at the children's hospital when my son was diagnosed."

"We were referred to a specialist hospital for help."

"We were given some leaflets at the hospital about hydrocephalus and a pamphlet for the Shine charity. The focus was on preparing her for surgery and dealing with post surgery recovery. There was not much information about living with the conditions. We were put in touch with a psychologist at the hospital."





## We asked if you received enough support at the time of diagnosis

Yes a lot. I continue to receive a lot of support now also.”

No. Apart from 6 month MRIs we didn't have much contact with the hospital. We don't live in catchment area for the hospital where my son was treated. Our local hospital is not great...”

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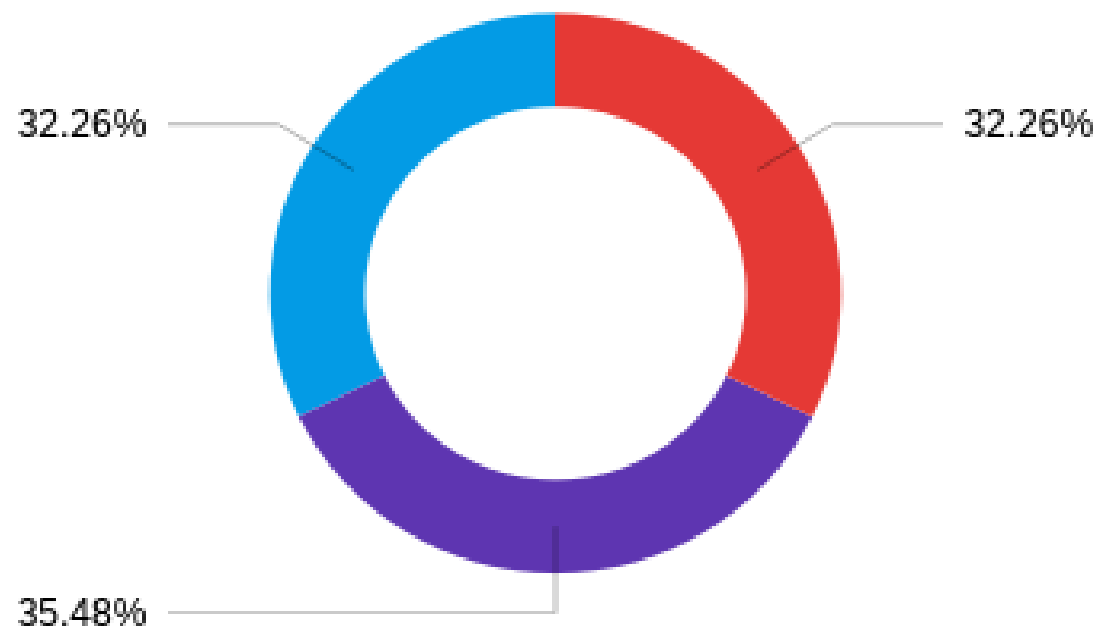
Surgery happened at the beginning of lock down so the support we received was vastly reduced from what is normally available. More information about looking after a child with the condition would have been nice. We were invited to ask questions but it's hard in the moment to know what to ask. Especially when you're in shock because your child, who you believed was completely healthy has been diagnosed with something you've never heard of

Not while pregnant, only from our cleft palate nurse when born. then eventually when he had his shunt at another hospital we felt supported

Not enough we did have a fantastic neuro nurse who visited often and provided a lot of information however it took almost 12 months for our daughter to have follow up from having her shunt fitted to have a baseline CT...”



We asked about the support you would have been interested in receiving at time of diagnosis



 An online forum for parents/carers.

 A support group for parents/carers hosted by other parents/carers

 A support group for parents/carers hosted by a Medical professional



## We asked you to share anything else that you felt you wanted to tell us

“A Facebook group has been supportive. Now my baby is 2.5 years, we have lots of support packages in place, but feel I have pushed a lot of these and educated myself. but thank the NHS. I feel someone else might be missed if they don't push for things or believe medical professionals about prognosis. my baby is doing amazing .”

“I have found it very frustrating that when we were sent home and I called the hospital because I had concerns, I felt we really had to battle to get her seen. My daughter and 8 surgeries between March and June including several shunt revisions so I would have liked to feel like we could take her straight back to the neuro ward if we were worried. Every time I was afraid something was wrong, it was a struggle to get her seen and made a stressful situation even worse.”

“feel that there is little support for parents from other parents with similar lived experience which would have been useful to have at diagnosis and afterwards as it's hard to explain the process of shunt revision when it happens to friends and family as although they can empathise they don't really understand and often have their own feelings towards it as it also impacts them.”

“Support about the medical side has been excellent. I have found it harder to get concrete information about impact on learning / social development etc as he has gone to school. Shine has a useful pack I have recently discovered.”



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With thanks to  
students at the Royal  
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survey input



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