UK National Screening Committee (UK NSC)

Screening for Cytomegalovirus

Date: 25 June 2026

Contents

Aim

This document provides background on the agenda item addressing the systematic review on newborn screening and an evidence map on antenatal screening for Cytomegalovirus (CMV).

Current Recommendation

The current UK NSC recommendation is based on an evidence review carried out by Bazian Ltd in 2017. The review aimed to evaluate the volume and direction of evidence published since the previous UK NSC review with a focus on newborn screening. Maternal screening was not included in the 2017 UK NSC review as following a scoping search of the literature no significant new evidence in support of antenatal screening was found.

Although the 2017 review identified polymerase chain reaction (PCR) assay of saliva samples as a candidate for newborn screening test, the overriding issue remaining was that even if the test can detect congenital CMV with sufficient reliability, none of the studies reviewed reported longer-term disease outcomes. Therefore, it was not possible to evaluate how screening test results correlate with the likelihood of

adverse outcomes. The review found that there was not a clear treatment option for babies with asymptomatic congenital CMV infection. As screening would be likely to identify a greater number of infants with cCMV, the majority of whom are likely to have minimal symptoms or no symptoms, and the management and treatment approach for these children was unclear, it was not possible to evaluate the harm and benefits for such screening. Since it was unclear how to identify babies who might benefit from treatment, the UK NSC concluded that there was not enough evidence to support the introduction of newborn screening for CMV.

In 2021 an evidence map was undertaken by Costello with the scope to evaluate the volume and type of evidence in relation to key issues associated with screening for CMV and to assess whether a more sustained review on screening for CMV should be commissioned at this time. The evidence map concluded that although some studies identified possible markers to distinguish which cCMV-infected newborns will suffer long-term negative outcomes, there was no consensus about the predictive value of such markers or their reliability. There was also insufficient evidence on any benefits of early treatment or intervention compared to late treatment after the presentation of symptoms. A single study was available, but it was unsuitable for drawing conclusions on the effectiveness of the interventions. Therefore, it was unlikely that at the time further evidence synthesis work on this topic would lead to a change in the UK NSC's position.

2025 evidence review work

Systematic review of newborn screening

To evaluate the potential benefits of newborn screening for cCMV, the UK NSC commissioned the York Evidence Synthesis Group to review existing studies on whether tests for newborns (up to 28 days old) can identify which babies are likely to develop long-term complications and would benefit from early treatment. Out of 217 studies identified, data were extracted from 171. Among these, 39 studies assessed the accuracy of saliva and dried blood spot tests, both of which were found to be highly effective, likely detecting over 90% of cCMV cases, suggesting they could be suitable for newborn screening.

Another 97 studies investigated various tests and characteristics to predict which newborns with cCMV might suffer long-term sequela. While the evidence was generally limited, the most consistent predictor of future complications was the presence of symptoms at birth, especially hearing loss. There was also some indication that MRI scans could help detect developmental issues.

In addition, 37 studies examined newborn screening programmes for cCMV, but none directly compared screening to current practice. As a result, there is no clear evidence that screening offers benefits over existing approaches. Universal screening would detect nearly all cases including asymptomatic babies who are unlikely to be harmed by the infection, potentially leading to unnecessary follow-up and treatment, with consequent distress for the family and overtreatment for the baby. Other approaches, such as testing only babies who fail the newborn hearing test, has been considered as a possible option to avoid overtreatment, but although

it would identify most symptomatic cases, it would miss babies with different symptoms.

In conclusion, although a substantial amount of new research was identified on newborn screening for cCMV, it does not yet provide sufficient evidence to support its implementation. Further studies comparing screening with standard care are needed to determine whether it delivers more benefits than harms for children.

Evidence map of antenatal screening for CMV

The 2021 consultation's responses on the UK NSC evidence map on newborn screening for cCMV indicated that there was emerging new evidence on oral valganciclovir treatment showing effectiveness in preventing vertical transmission. For this reason, it was agreed to include antenatal screening for CMV in future evaluations of the evidence. In 2024 the UK NSC commissioned the York Evidence Synthesis Group to develop an evidence map to evaluate the volume and type of evidence on the existence of non-invasive antenatal screening tests to detect maternal CMV infection, the evidence on the value of antenatal treatment to prevent cCMV infection or cCMV-related morbidity and mortality in the newborn, and the evidence on fetal tests to determine the severity of cCMV. The aim of this evidence map is to assess whether a more sustained review on antenatal screening for CMV should be commissioned.

The evidence map concluded that with regard to screening for CMV infection in pregnancy, there is a large body of evidence to suggest that first trimester immunoglobulin testing using IgG and IgG avidity testing in combination with IgM testing could have good accuracy for detecting primary maternal CMV infection and so help to identify subsequent cCMV infection in the newborn. Primary infection in early pregnancy has a lower transmission rate than in later pregnancy (the rate can increase from roughly 20% to 75%); however, it is believed that if primary CMV infection occurs periconceptionally or in the first trimester of pregnancy, it can impact fetal development and result in severe abnormalities. It should be noted that IgG avidity and IgM testing will not detect non-primary CMV infection. However, the remission rate from non-primary CMV infection is apparently rare. Evidence on other possible tests for CMV infection is limited.

There is a large body of evidence to show that treatment with oral valganciclovir substantially reduces the rate of transmission of CMV to the fetus. However, there is currently only 1 published randomised controlled trial on this topic. There is also evidence on hyperimmunoglobulin (HIG) treatment, but studies varied in their conclusions as to whether it was effective at reducing the rate of CMV transmission.

There is also a broad range of evidence on tests to identify cCMV infection with the aim of preventing long term harms in the baby. There appears to be evidence that fetal ultrasound, possibly in combination with fetal magnetic resonance imaging (MRI), could detect abnormalities indicative of long-term sequela, especially that a negative test result can "rule out" long-term harms. There is some, more limited, evidence that CMV viral load in the amniotic fluid could predict long-term harms for the baby.

Given the large volume of evidence of antenatal screening for CMV it is recommended a full evaluation of the evidence for all three components of this evidence map. It may also be desirable to examine whether an antenatal CMV screening programme as a whole is clinically effective and cost-effective, and whether it is acceptable to pregnant women and the medical community.

Research and methodology group meeting

As the systematic review and the evidence map highlight gaps in the evidence and proposed research to fulfil such gaps. To investigate these recommendations and determine whether further work was required, these evidence products were discussed at the July RMG meeting.

The discussion highlighted the complexity and uncertainty surrounding both antenatal and newborn screening for cCMV. Universal newborn screening would detect most cCMV cases, but since around 90% of infected infants show no symptoms, most would not qualify for antiviral treatment under current guidelines. These asymptomatic cases might receive increased hearing monitoring, but the absence of a clear clinical pathway raises ethical and practical concerns about the value of screening without intervention. Other approaches, such as testing infants who fail hearing assessments, could be a more focused and likely to identify those who could benefit from treatment, though it risks missing other cases.

First trimester testing using IgG and IgM can identify women with primary CMV infection, who are at higher risk. Treatment with oral valganciclovir may reduce transmission, but evidence on adverse effects is limited. While antenatal screening could potentially prevent transmission, more research is needed to confirm outcomes and safety. Although the risk of adverse outcomes in children born to mothers with primary infection is considered relatively low, detection is difficult due to the asymptomatic nature of maternal infection and the possibility of infection at any stage of pregnancy. The group noted that due to the lack of evidence, concerns remain about the long-term effects of antiviral treatment during pregnancy.

Despite these uncertainties, there is interest in antenatal screening, even if treatment effectiveness is unclear, as it could lead to closer monitoring of newborns. The group agreed that foundational work is needed before any screening programme is introduced. This includes assessing the current disease burden, understanding variations in practice, and evaluating the benefits of intervention. A key recommendation was to identify the key knowledge gaps which, if addressed, could improve the case for screening whether antenatal or newborn.

Actions

The UK NSC is asked to note the consultation responses and approve the recommendation.

UK NSC recommendation

1. Newborn screening for cCMV is not recommended, as there is insufficient evidence to demonstrate that such a screening programme would offer clear benefits over existing clinical management. Further studies comparing screening with standard care are needed to determine whether it delivers more benefits than harms for children.
2. Further work should be commissioned to formally review the body of evidence on antenatal screening which was retrieved by the evidence map. The outcome of this would be subject of a future consultation exercise.

Consultation

A 3-month consultation (14 November 2025 – 6 February 2026) was hosted on the UK NSC website. Direct emails were sent to 10 stakeholders. (Annex A)

Comments were received from the following stakeholders:

1. Chrissie Jones, Professor of Paediatric Infection and Immunity, University of Southampton
2. Emma Burns, Leicestershire County Council
3. Oliver Toovey, onsultant Virologist, University Hospitals of Leicester NHS Trust
4. Peter Muir, Consultant Clinical Scientist, UKHSA Clinical Network Laboratory Bristol
5. Elske Schouten, COO, MRC Holland
6. CMV Action Charity
7. Professor Hermione Lyall, Imperial College Healthcare NHS Trust; behalf of the seven national bodies listed below:
8. British Paediatric Allergy, Immunology and Infection Group (BPAIIG)
9. President – Dr Jonnie Cohen
10. UK Congenital CMV Infection Collaboration (UKCCIC)
11. Leader – Dr Helen Payne
12. Congenital Infection, Education and Treatment (CONCEPT)
13. Leader – Dr Eleni Nastouli

14. British Association of Audiovestibular Physicians (BAAP)
15. President – Dr Shankar Rangan
16. British Association of Paediatricians in Audiology (BAPA)
17. Chair – Dr Jo Harris
18. National Deaf Children's' Society (NDCS)
19. Chief Executive Officer – George Crockford
20. British Academy of Audiology (BAA)
21. President – Dr Claire Benton
22. Kate Dinwiddy, British Association of Perinatal Medicine

A total of 103 members of the public responded to the consultation.

Summary of comments by topic and responses

Personal stories of diagnosis and treatment

There is a strong, widespread support for routine CMV screening from members of the public who submitted comments in response to the consultation.

They emphasised that congenital CMV can have a profound and enduring emotional, physical, and social impact on affected individuals, parents, carers, and wider families. Accounts describe experiences of stillbirth, and serious neonatal complications, as well as a range of severe long-term outcomes including hearing and vision impairment, cerebral palsy, microcephaly, developmental delay, epilepsy, and significant mobility limitations. They consistently highlighted the profound grief, trauma, guilt, and long-term mental health consequences associated with these outcomes. Many also described substantial strain on family life, including financial hardship and disruption to employment and careers, with some parents leaving work entirely to provide ongoing care. Several submissions explicitly referred to life changing loss and lasting family distress, underlining the significant human burden associated with congenital CMV.

Stakeholders consistently highlighted that:

- CMV is common, often more common than other conditions for which screening is already implemented in newborns and in pregnancy (for example, Down's syndrome)
- screening could prevent severe outcomes, enable early treatment, and give families time to prepare
- screening would reduce anxiety, uncertainty, and diagnostic delays. Late or missed diagnosis has significant clinical and emotional consequences: without universal screening, many babies are diagnosed too late for optimal antiviral

treatment and appropriate monitoring (particularly for hearing), leaving parents feeling let down and resulting in missed opportunities for intervention, support, and reassurance

- the UK lags behind other countries (for example, USA, Belgium, France) in CMV screening and treatment

Absence of CMV's education across healthcare and public settings.

Stakeholders highlighted a widespread lack of awareness of CMV among healthcare professionals and the public, with clinicians often not recognising symptoms or providing incorrect advice, parents frequently learning about CMV only after diagnosis when interventions were no longer possible. Many comments mention that charities, not the NHS, are currently providing the bulk of information.

They called for improved education and preventive guidance alongside screening. This included providing clear information at booking appointments, offering hygiene advice for pregnant women, and wider awareness campaigns across public, healthcare settings, and in high-risk workplaces (for example, nurseries and schools). They also highlighted the importance of the inclusion of CMV information in pregnancy packs, strengthening professional training, and incorporating CMV into routine public health messaging, noting that basic prevention behaviours could reduce transmission if people were simply informed. They noted that basic prevention behaviours could reduce transmission if people knew about them.

Missed opportunities for diagnosis and treatment

Stakeholders stressed that early testing frequently did not occur, resulting in missed opportunities for timely antiviral treatment, delayed or inconclusive diagnostic testing, unrecognised maternal infection in early pregnancy, and widespread frustration that avoidable harm occurred because CMV was not considered.

In general, stakeholders noted the need for better support pathways after diagnosis. They describe the frequent lack of guidance after diagnosis. Some family members described feeling "abandoned" or "left to Google" for find answer. They also indicated difficulties in accessing treatment, therapies, or coordinated care. Therefore, they asked for a clear clinical pathway, more tailored monitoring for infants with CMV and more family support services, counselling, and financial support.

Several contributors emphasised the ethical importance of informed choice. They explained that screening empowers parents to make well□considered decisions about whether to continue a pregnancy and ensures that they receive crucial information before irreversible harm occurs. Without screening, parents are deprived of reproductive autonomy, which can lead to preventable trauma. A number of stakeholders also noted that, had they been informed earlier, they may have made different decisions about their pregnancies.

They highlighted that missed cases of CMV result in an economic burden on the NHS, arguing that a simple and inexpensive screening programme could reduce

long-term costs by preventing the need for complex diagnostics, ongoing healthcare, surgical interventions, and special education support.

Inequality and inconsistency across the UK in care and services

Stakeholders raised concerns about inequality and inconsistency in care and service provision across the UK, highlighting considerable variation between regions, hospitals, and individual clinicians. They emphasised that outcomes can depend heavily on chance (for example, whether a clinician happens to consider CMV as a possible diagnosis) leading to what is perceived as an inconsistent and unfair system. In particular, targeted pathways are applied unevenly: testing for babies who do not pass the newborn hearing screen varies widely between NHS trusts, creating a postcode lottery that affects timely diagnosis and access to treatment, despite evidence that targeted screening can identify cases that would otherwise be missed.

Response

The UK NSC are grateful to those individuals who took the time to respond to the consultation to give powerful accounts of the profound impact congenital CMV can have on children and families. Be assured that the Committee both value and carefully consider these perspectives alongside the scientific evidence.

We understand that when antenatal or newborn screening could have prevented or mitigated against the devastating effect of undiagnosed congenital CMV, it can be difficult for families to accept that testing for the condition is not being prioritised for implementation. However, the UKNSC has to think about the implications of screening when it will be offered to hundreds of thousands of women and their babies. For this reason, introducing a national population screening programme must be based on systematically reviewed evidence to ensure that screening brings more benefit than harm at a population level.

The UK NSC will continue to keep the evidence under review as new research and data become available. In addition, the Committee is actively exploring new approaches across a broad range of newborn blood spot conditions to help researchers expand the evidence base.

The UK NSC notes the strong public support for routine screening and the arguments presented regarding potential benefits, including earlier diagnosis, reduced uncertainty, and improved preparedness for families. The Committee also recognises calls for improved education, preventive guidance, and clearer clinical pathways, and notes that these issues highlight broader concerns around awareness, consistency of care, and post-diagnostic support within current services. The UK NSC also notes the need for national standardisation of follow-up and management practices. The Committee recognises that concerns about awareness, inequality, and post-diagnostic support may warrant consideration beyond population screening discussions alone.

The UK NSC's role is to assess population screening programmes against its established screening criteria. While congenital CMV is associated with substantial morbidity and family impact, previous evidence reviews have identified important uncertainties, including limitations in predicting which infants will develop long-term

complications, uncertainty about which individuals would benefit most from treatment, the potential for overdiagnosis and unintended harms, and gaps in comparative evidence demonstrating that screening leads to better outcomes than current practice. The UK NSC recognises these evidence gaps and is keen to promote and support research to generate the comparative evidence needed to inform future screening recommendations.

Stakeholders perceived that the UK lags behind other countries that screen for cCMV. The UK NSC seeks and uses evidence from all around the world. Test accuracy, effective treatments and diagnostic tests are not country specific so information from other countries is useful and incorporated in the evidence summaries. However, test performance can vary by geographical population; the number of babies affected per thousand births might differ between countries because of ethnic or genetic differences. Acceptability of screening is not universally the same for all countries. There are significant differences between countries in terms of diagnostic test and treatment services, the treatments approved, who pays (the state or the individual or insurance companies), and who approves the use of the drugs. The National Institute for Health and Care Excellence (NICE) only works in England and Wales. All these factors need to be taken into consideration when a decision to implement a universal screening programme is made. For this reason, the UK NSC is keen to recommend research within the context of the NHS.

The UK NSC will consider the views expressed in this consultation alongside the findings of the commissioned systematic review and evidence map, and within the context of its remit and screening criteria, when developing its recommendations.

More work and research is needed

In general, the stakeholders agreed with the conclusion that, based on the findings of the antenatal evidence map, there is sufficient published literature, including primary research and systematic reviews, to justify commissioning further work on antenatal screening for CMV in line with the UK NSC evidence review process. They encouraged the UK NSC to undertake this work as soon as possible and perhaps to expand the scope of the evidence review.

Response

The antenatal report was produced as an evidence map, designed to scan the published literature in order to identify the volume and type of evidence available and to inform whether there is sufficient evidence to commission a more sustained analysis on this topic. As such, it was deliberately limited in scope and focused on 3 key areas: the accuracy of screening tests, treatment for maternal CMV, and fetal testing.

Evidence maps do not provide a detailed description of the condition or assess all potential impacts. Therefore the report was not intended to cover wider outcomes such as pregnancy loss or the full spectrum of fetal and long-term sequelae. More detailed and comprehensive information would be expected as part of a full evidence evaluation. We agree that any future systematic review should consider the broader scope, including an updated and more detailed description of CMV in pregnancy and

its impact on the fetus, drawing on the most recent epidemiological data on prevalence and long-term outcomes.

Absence of comparative studies

Several stakeholders agreed that the current evidence base for cCMV screening is limited by the absence of comparative studies assessing screening against standard care or ad-hoc testing without screening.

Response

Existing evidence from screening programmes is largely non-comparative and therefore of low quality, making it difficult to assess the true benefits of screening for newborns. Although randomised trials may be challenging to undertake in this context, there remains a clear need for trials or high-quality real-world evidence that compare outcomes with and without screening.

In the absence of such evidence, it is not currently possible to determine the extent to which newborns would benefit from cCMV screening, and therefore neither universal nor targeted cCMV screening can be recommended for implementation at this time. The UK NSC recognises these important evidence gaps and supports further research to address them, including research to inform the practical implementation of neonatal screening and to determine the most appropriate screening pathways. Such research would be valuable in supporting any future considerations of cCMV screening.

Evidence from other countries

A stakeholder noted that there is growing international evidence indicating that neonatal and maternal CMV screening is feasible and can improve outcomes by enabling early treatment and risk-reduction measures, particularly in light of new data showing improved hearing outcomes following treatment. They also highlighted the recent introduction of national maternal screening in France and noted that, in the absence of an effective vaccine, screening currently represents the only available strategy to reduce lifelong harms to infants.

Response

Thank you for sharing this additional information. In line with the UK NSC process, the neonatal review was based on evidence identified within the predefined search dates, and it is not possible to formally incorporate evidence published after the search period. Any new evidence would need to be considered through the established UK NSC processes.

It is, of course, to be expected that additional evidence will continue to emerge following the completion of a review. We did note a small number of papers that were shared outside the original publication timeframe. While these could not be formally included, our assessment is that their inclusion would not have materially altered the overall conclusions of the neonatal review. We would also highlight that the report already acknowledges the importance of emerging research, particularly from the USA and Canada, in informing future considerations around neonatal

screening (see Newborn report, page 95). We agree that evaluating emerging evidence from the USA, Israel and Canada will be important, as stated in the research recommendations of our report.

Prevalence of long-term problems

Some stakeholders questioned whether the report underestimates the number of babies experiencing long-term sequelae from cCMV, arguing that more recent evidence suggests a substantially higher burden of disease and that relying on conservative estimates may downplay the true impact and weaken the case for screening.

Response

The estimate that approximately 202 to 216 babies born in the UK with cCMV will experience long-term problems was based on the best available evidence at the time of writing, as cited in the report, and was agreed by our clinical advisers. We also note that the rate of long-term sequelae identified in the studies included in the review was around 18% (see Newborn report, Table 18; predicted rate 1,757 per 10,000 newborns with cCMV), which is consistent with the estimates reported in the recent *Lancet* publication.

Predicting long-term problems and argument against universal screening

A stakeholder raised concerns that the report's approach to predicting long-term outcomes relied on factors (symptoms at birth, MRI findings, timing of maternal infection) that in practice are often unavailable because many babies are not tested for cCMV. They also highlighted an inconsistency in rejecting universal screening that would identify infants who may never develop symptoms while also rejecting targeted screening that may miss asymptomatic cases. They argued that this could mean children who go on to suffer serious long-term harm are overlooked.

Response

Stakeholders noted that while there is emerging evidence that MRI, ultrasound findings, and the timing of maternal infection may help predict long-term adverse outcomes such as epilepsy, these predictors are often missed in practice. Inconsistent testing and guidance mean that many asymptomatic or unrecognised cases are not identified and therefore do not undergo further investigation, leaving symptoms at birth as the only predictor routinely considered. We agree with the observation that, aside from clinical symptoms, other approaches to predicting long-term outcomes will not be considered unless a baby is tested, as tools such as MRI are typically only undertaken once cCMV screening has identified a positive case.

We acknowledge the points raised by stakeholders regarding the potential limitations of both universal and targeted screening approaches. It is correct that, under a universal screening programme, many babies who test positive would not go on to develop long-term sequelae related to CMV. It is also correct that a targeted approach, such as screening following the newborn hearing screen, would miss

some asymptomatic cases or those without hearing loss. These are not contradictory conclusions but reflect different limitations that need to be weighed when considering the potential impact of any screening strategy.

We therefore do not agree that the report fails to consider these approaches alongside one another. Rather, our assessment is that there is currently insufficient high-quality comparative evidence to determine the impact of either universal or targeted cCMV screening, or to robustly compare the benefits and harms of these approaches. This lack of evidence underpins the report's conclusion and highlights the need for further research in this area.

Testing after newborn hearing screen

One stakeholder argued that the report overlooks the practical and clinical unacceptability of relying on ad-hoc testing after symptoms emerge, which they say leads to missed opportunities for timely diagnosis and antiviral treatment, underestimates the true burden of disease, and fails to reflect parents' and clinicians' concerns about babies missing out on effective early intervention.

Response

We note that the key finding in our report is that the studies required to demonstrate that screening (universal or targeted) would be beneficial have not been conducted. Hence our position that "it remains to be shown that targeted screening and subsequent antiviral therapy leads to better clinical outcomes than ad-hoc testing for cCMV or treating symptoms as they emerge". This is not a claim that current practice is acceptable or appropriate; just that evidence is lacking to demonstrate the value of screening.

Lack of involvement of the public and families

Some stakeholders were disappointed that the public and families were only being involved at the consultation period, instead of the patient experience being part of the evidence presented.

Response

The reviewers were supported throughout the project by an advisory group, which included members of the UK NSC Fetal, Maternal and Child Health (FMCH) group, patient and public voice (PPV) representatives, and external members, including a charity supporting families and individuals affected by the condition. The advisory group was established specifically to support the reviewers across all stages of the project and provided input on both the review protocol and the final report.

Engagement took place through online meetings and written correspondence. The perspectives of all advisory group members were considered equally and were extremely important in shaping the approach, interpretation, and conclusions of this work. The reviewers place significant value on this input, which played a critical role in ensuring the review was robust, balanced, and informed by lived experience as well as clinical and methodological expertise.

Changes to the documents post-consultation

Some stakeholders asked for clarifications and suggested some changes to the consultation documents to clarify and amend data with newer evidence.

Response

The reviewers examined all the stakeholders' suggestions. Changes and clarifications were made to the consultation documents where appropriate.

Annex A: List of Organisations Contacted

1. British Association of Paediatricians in Audiology (BAPA)
2. British Paediatric, Allergy, Infection and Immunity Group (BPAIIG)
3. CMV Action
4. Royal College of General Practitioners
5. Royal College of Obstetricians and Gynaecologists
6. Royal College of Paediatrics and Child Health
7. Royal College of Physicians
8. Royal College of Physicians and Surgeons of Glasgow
9. Royal College of Physicians of Edinburgh
10. The British Association of Audiovestibular Physicians

Annex B: Consultation Responses

Note: Personally identifiable information has been redacted from certain comments, where individuals have chosen not to have personal details made public.

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

My daughter was born at 23weeks gestation. She apparently contracted CMV from my breast milk. We don't know if her disabilities (cerebral palsy, CVI, autistic) were caused or contributed by CMV, or due to her being extremely premature.

Recommendation comment:

Yes, CMV should be screened for routinely. There are too many disabilities being diagnosed without no rhyme or reason as to why.

Alternatives comment:

There isn't enough support for children, parents and families. Many times I've been handed a leaflet and left to get on with it. Minimal support in school.

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

I am a mother to a lovely beautiful 6 year old. My daughter was born with CCMV she is severely affected to the point she is non verbal, non mobile, hearing loss, eyesight loss, peg fed, posture issues,

America is more advanced in the care of CCMV to the point mothers get offered anti virals and have screenings to check for CMV. UK barely have anything.

In ultrasounds my daughter was measuring small from the very start what would have been my 12 week appointment she was measuring 9 weeks. This went on for for basically the whole pregnancy and I was offered frequent appointments to monitor the

blood going to the cord and to her brain her cerableam was a different shape compared to a normal one at 31 weeks I got offered amniocentesis as they thought she has Down syndrome. I got results a week later to say se has CMV which we have never heard of before.

I had an appointment on Monday morning for her blood and nutrients being monitored I was told to come back the Wednesday morning I had a fetal medicine appointment later on that morning which I couldn't attend due to the first hospital keeping me in. The words I can always remember was your child will be born between 3 and 6 tomorrow which had been a Thursday. I was closely monitored that Wednesday night and the whole of Thursday until I had an emergency c section at 3pm my daughter was born XXXX XXXX (small for gestational age). If I wasn't offered them appointments and one more day in the womb I dread to think she wouldn't be here today.

It's very essential this gets passed and mothers and children get screened for this and both get offered anti virals. With the proper care and screening and wth anti virals offered early to them both the child born isn't severely affected with disabilities the child born may have some difficulty's with hearing loss etc but not half as bad with early intervention.

Evidence Comment:

No. But I'm very lucky they looked into why my child was measuring small at 20 weeks 30 weeks.

I'm very pleased to say that they caught into something was right here let's get something done. With the proper screening it can be caught even earlier than being offered an amnio with a big ass needle going into your child's sac. I was on eggshells after as there's so many risks involved in this alone to the point you can lose your child after this test. A simple cmv screening and proper blood test cancels out the risk of an amino

Discussion comment:

Get it passed asap

Recommendation comment:

Definitely recommend it's very much needed in ni and the rest of the UK

Alternatives comment:

Get the screening passed and in place and offer mothere the anti virals as well

Other comments:

More needs done in the UK for CMv screening

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

Our son was born covered in purple spots, we were told from a quick delivery! There needs to be more education on this, as when he lost his hearing aged 3.5 yrs we were told that was due to cCMv. We'd never heard of this. Our son is now bilaterally implanted with cochlear implants.

He may have been eligible for medication that could have saved his hearing had the midwife and hospital staff have more knowledge.

One of the signs is being covered in spots (pechti).

Medication may have saved his hearing and saved him and us the heartache of being completely deaf and losing speech and having operations and difficulties in school and socially and saved the government the costs of all the above).

Recommendation comment:

Yes- screening should be recommended.

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

Screening of pregnant women to identify if they haven't had CMV so they can take precautions whilst pregnant this would dramatically reduce the outcome our family had when my niece was born with CMV the cost to the NHS for her on going care and treatment is far greater than a £12 screening in pregnancy which many women would pay for like they do 4D scans! My niece is deaf partially sighted has quad spastic celebral palsy recent Scoliosis surgery is non verbal just a small list of her medical needs. Those who go through IVF are pre screened for CMV we need to be proactive to protect the NHS. Educate those at risk and screen knowledge is power. I know if my XXXX XXXX had the knowledge XXXX XXXX would have stopped kissing XXXX XXXX toddlers on the lips at bedtime, not shared utensils, protected sex just a few of

the very easy basic things if you know you can do to protect your unborn child being harmed by CMV

Evidence Comment:

CMV is the largest cause of deafness in children its is more common than down syndrome which is screen for.

To my knowledge no families with children born with CMV have been contacted through their NHS team to get true data on the ongoing challenges and financial drain CMV is on the NHS

Recommendation comment:

Those who go through IVF are pre screened for CMV we need to be proactive to protect the NHS. Educate those at risk and screen knowledge is power. I know if my XXXX XXXX had the knowledge XXXX XXXX would have stopped kissing XXXX XXXX toddlers on the lips at bedtime, not shared utensils, protected sex just a few of the very easy basic things if you know you can do to protect your unborn child being harmed by CMV

Alternatives comment:

Mass education programs similar to the list of foods you aren't allowed to eat whilst pregnant that carry far less risk than CMV does to your unborn child

Other comments:

Mass education programs similar to the list of foods you aren't allowed to eat whilst pregnant that carry far less risk than CMV does to your unborn child

Brie nuts cat litter add bodily fluids to the list kissing on the lips, nappy changing, sharing utensils drinking cups it's not rocket science if you have awareness

---

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

It has affected myself and my family having a daughter born with Congenital CMV.

Evidence Comment:

It should be screened for. I spent my entire pregnancy at our local MAU, sometimes twice a day, I felt ignored and let down by the nhs and midwife's, one midwife made

me cry at 3 in the morning and for me to discharge myself. Being an advocate for my own body and thinking something wasn't "right" but having commented made about me being there feeling like I was in the way or wasting time. My daughter was 7 months when we got her diagnosis of CMV she missed out of vital treatment to prevent anything deteriorating, due to the lack of knowledge of CMV as we had been in hospital prior to the last stay. Now she runs the risk of becoming deaf and blind as well as developing more disabilities.

Recommendation comment:

It should be screened for it's the leading cause which is not genetic for childhood disabilities and child deafness. It's more common than down syndrome yet there is no awareness or it isn't screened for. That needs to change. My beautiful daughter because of this virus will never talk or say she loves me, I will never hear her call me mummy.

She has a severe learning disability.

Global delay.

Afrid

Pica

Profound hearing loss in her right and they believe now that she has a significant hearing loss in her good ear.

Her eye sight is deteriorating

They believe she's developed epilepsy.

She's non Verbal

She has significant changes on her brain

She's only 6, it breaks my heart to think what our future holds. The system is already so broken what's it going to be like when she's an adult if we're still lucky to have her with us in another 15/20 years. Or how will I cope? We already have to fight for the most basic things, all because of a virus and no awareness or no screening even though I was always asking for help during my pregnancy and beyond when she was born.

Alternatives comment:

Make awareness, put information in pregnancy packs, ensure employers have correct ppe for women who are pregnant and work alongside children

---

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

My daughter is significantly disabled and is in palliative care

Recommendation comment:

Because would save thousands of baby's being born with such significant long lasting disabilities

Alternatives comment:

Offer a antiviral for cmv as this could stop cmv attacking the baby

---

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

I had ccmv in pregnancy and my son was born with the virus..

we are one of the lucky ones as my son doesn't have any symptoms from the virus.

Recommendation comment:

I think screening should be made compulsory..

many cases get missed until

It's to late for medication to help

Alternatives comment:

I think that the nhs should be educated more about cmv. My son is 23 and I've spoken to many professionals over the years who have no clue what cmv is. 23 years ago a consultant told me I had the virus and said he needed to consult his medical book as he had never had any contact with anybody with it before. I was told to search it on the internet!!

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

My son was diagnosed with CMV around 24/25 weeks around the second trimester. Our hopes and dreams were dashed as the medical advice was the terminate this pregnancy due to his extreme brain abnormalities amongst other issues. I had no knowledge of the disease which I apparently caught in the first trimester. This could have been prevented but i had never heard of it. We are a very clean family i work in health but i had never of it neither had my gp or anyone i spoke to. My son was still born at 32 weeks. I had to make the decision to end his life whilst he was still alive and kicking in me. I still feel the guilt and despair from this. I was placed on the maternity after he died. This again was really painful.

Evidence Comment:

Nurseries should undertake regular screening for CMV

My cmv result as part of my initial bloods came back positive but no one communicated this to me.

Specialist support is needed to support women before and after diagnosis

Recommendation comment:

It must happen because there will be more women who's baby's contract cmv. This terrible disease does everything but kill the foetus. Its terrible and women can be left like I am.and my husband with immense trauma, guilt and sadness. It is preventable but those wome. Who have Nursery age children need to be screened to ensure they do not contract cmv during the first trimester.

Other comments:

Provide informatiomation and advice about screening to women of all backgrounds using community workers and pay them to do this.

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

My Daughter lost her first baby, my Grandson at 35 weeks due to the impact of cCMV

If she had been informed about CMV at her first midwife appointments and screened things would be very different, plus she works in a Nursery which is a huge risk of catching, infections and viruses

Something needs to change, a simple poster in the doctors waiting room could get the message out there, charities shouldn't have be the voice

We are still grieving, and will probably never get over our loss

Recommendation comment:

Screening for pregnant Mothers and Newborns are a must

Alternatives comment:

Inform, educate, im shocked how many health professionals hadnt heard of the virus,

Surely the community midwifes should be an expectant mothers first source of information, its not the only virus that can harm a baby

Get midwifes educated at the maternity units, so they can look for signs, do they recognise the rash these babies can be born with and the antiviral meds the babies will need

Other comments:

Get everybody educated,

Posters in doctors, dentists, scan departments childrens centre, Nurseries

---

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

My niece was born with CMV

Evidence Comment:

Screening is SO important, if it was caught earlier, my niece wouldn't have been born so disabled

Recommendation comment:

YES ABSOLUTEL

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

Yes I found out my daughter had contracted congenital cmv during my pregnancy if I knew earlier maybe I could have had anti virals if I knew I would've had much better support in the medical fields.

She is severely affected and I know this could've been avoided.

Recommendation comment:

Should be recommended – as per my comments above it could help a child in the future hopefully resulting in a much better outcome than my child- more awareness and more support for future parents

Alternatives comment:

Raising awareness, offer leaflets a conversation with the midwife about the risks the virus and how to avoid it.

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

My daughter was born 31 years ago with this condition

Recommendation comment:

Screening should be recommended

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

My daughter who is now one year old now, she failed two hearing tests when she was born which too almost 3 weeks for the hospital to test for cmv

Evidence Comment:

It took two failed hearing tests and 3 weeks for the hospital to decide on testing her for cmv. The medication she was given to treat cmv was given to her when she was 27 days old, when the optimal date to start the medication is at 28 days old. Which in my opinion is way too close for it to have good affects on my daughter.

She also has cysts in her brain and multiple movement delays because of her equilibrium being off as she is completely deaf in one ear because the cmv attacked it within the first 16 weeks of the pregnancy.

Discussion comment:

I believe that cmv isn't taken seriously in this country.

The nhs test for multiple things during pregnancy so why can't cmv be tested too.

Recommendation comment:

Screening should happen because it will save and help so many children who suffer with the disease.

Alternatives comment:

Actually listen to the people who fundraise for cmv action.

Put money into research

Make it routine to check for cmv

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

This condition has affected my close family

Recommendation comment:

It should be performed

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

Our youngest daughter was diagnosed with cCMV at 2 months old after failing her new born hearing screen. She was a homebirth and therefore not tested in hospital so by the time we found out CMV was the cause of her deafness it was too late for the antiviral medication.

We had never heard of CMV and neither had our midwife team. Not once did anyone say be careful finishing your eldest's daughters food as this may have been how I contracted cmv. I was not unwell and nothing showed up on scans etc. some awareness and testing in the initial bloods would help so many. It is the most common cause of childhood deafness and so little is known about it. It is easily preventable.

Alternatives comment:

Raise awareness of the causes and the condition itself. Midwives could inform mums about this if they are at higher risk.

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

In June 2018 I had to have a termination for medical reasons due to my unborn baby having cCMV. I had never heard of the virus nor has most people who I speak to. Knowledge is critical and screening in my view is vital. It may not have prevented my situation as I was still pregnant but more needs to be done about this virus and needs to be mentioned at midwife appointments and should be tested when pregnant woman have bloods taken. For all the research I have done into the virus, knowledge and understanding is key. I have suffered as have many women going through it. The fear of the virus has resulted in me having councilling and my pregnancies that followed were filled with anxiety. I have had many interactions with CMV awareness and believe that the screening is so so important.

Recommendation comment:

Yes. Then people have facts and can find the appropriate support. The condition can be more widely known.

Alternatives comment:

More support and more funding.

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

My granddaughter was informed she had cmv at 24weeks pregnant, in her opinion too late to consider termination. The pregnancy has been extremely stressful with such an unknown life changing outcome.

Recommendation comment:

Should be recommended to enable parents to make choices early on in a pregnancy

---

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

Yes. My Grandaughter was born with the condition. This has left her completely deaf in one ear. Only recently having her first birthday, we have been informed that it is too soon to know if some of the other issues related to the condition will be a problem at a later time. She is regularly monitored for now.

Evidence Comment:

Not being medically trained, I am not sure if anything may have been overlooked.

Discussion comment:

Although not foolproof, like many other testing/screening methods, more precise results can be made, the more the system is used & tweaked from the accurate results made.

Recommendation comment:

Even though tests/screening may not be foolproof, If it can help diagnose even one third of mothers/babies with this condition, it is certainly worth doing.

Alternatives comment:

Again, not medically trained, but I would assume this condition can not be detected via blood tests ?

Other comments:

Neither my daughter or partner drives, Is there a way the government can implement an NHS bus pass for parents of babies with this condition, as the very regular appointments that they need to attend, are a financial drain, with us (The Grandparents) often having co contribute to the cost of travel.

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

I have a very good friends daughter who was born with cmv and we have seen 1st ha d how it has affected their family.

Recommendation comment:

It should 100% be screened for as early in pregnancy as possible so the families can be prepared.

Alternatives comment:

Alot mkre support and services for families

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

Our XXXX XXXX was born in 2011 with severe complications. After one week in the ICU we found out that XXXX XXXX had CMV. XXXX XXXX stayed in hospital for a further 8weeks. CMV has affected our family a lot. XXXX XXXX is now 14yrs old and CMV still affects XXXX XXXX a lot. If screening was available we could have got help or atleast been aware of the effects of CMV before birth.

Recommendation comment:

Screening for CMV should 100% be recommended there is not alternative.

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

My cousin was born with the virus and it has affected her mobility

Recommendation comment:

Yes

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

My child was born in Covid lockdown 2020. XXXX XXXX failed XXXX XXXX newborn hearing text and was never brought back to be tested in the specific time frame. This led to XXXX XXXX not receiving the anti viral. This has now led on being diognosed with severe autism, no -verbal, partial hearing loss, not being diagnosed with cmv until 3 years old and recently vestibular hypo function. At only 5 years old XXXX XXXX will need further tests throughout XXXX XXXX life to see if CMV affects XXXX XXXX any further. It's already affected XXXX XXXX severely due to not being picked up when XXXX XXXX was born.

Evidence Comment:

My child was born in Covid lockdown 2020. XXXX XXXX failed XXXX XXXX newborn hearing text and was never brought back to be tested in the specific time frame. This led to XXXX XXXX not receiving the anti viral. This has now led on being diognosed with severe autism, no -verbal, partial hearing loss, not being diagnosed with cmv until 3 years old and recently vestibular hypo function. At only 5 years old XXXX XXXX will need further tests throughout XXXX XXXX life to see if CMV affects XXXX XXXX any further. It's already affected XXXX XXXX severely due to not being picked up when XXXX XXXX was born.

Discussion comment:

Happy to speak to others about how we was failed and to meet my child and what the impact this condition has had on XXXX XXXX and us as a family.

Recommendation comment:

It should happen when every child is born to give them a chance if positive.

Alternatives comment:

Learn what cmv is. Every nurse and doctor we meet do not know what this condition is and people have never heard of it.

Other comments:

Make the condition more known to everyone.

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

18 year old daughter had acute cmv and still suffering 10 months later

Evidence Comment:

No

Discussion comment:

No

Recommendation comment:

All children should be screened and then st intervals and especially before pregnancy

Alternatives comment:

N/a

Other comments:

No

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Recommendation comment:

Should be as I know people personally who have been affected by this.

Alternatives comment:

Raise awareness

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

Yes it has affected your family,and there was no knowledge or awareness of thiit should s condition

Recommendation comment:

Yes it should be screening

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

My daughter was born deaf due to cCMV. It is thought she contracted the virus in the womb during the first trimester when my then 2 year old son had chickenpox. I did seek doctors advice as I knew that chickenpox and pregnancy wasn't safe but was advised that because i had chickenpox as a child that I would be fine. I was fine but my baby was not. There was no awareness or mention of CMV, I had never heard of it until I started looking for reasons for my daughters deafness as there is none in the family. We had a lucky escape with "just" a hearing loss but I'm aware of how severe CMV can be. It's routinely screened in America and I feel it should be here too

Recommendation comment:

To give parents the best chance of stopping life limiting conditions for their children

---

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

Our daughter was left deaf, with an acute vestibular disorder and food intolerances as a result of a cmv infection I had in pregnancy. She was hospitalised at 9 months with failure to thrive as she was so poorly and no one knew why. The cost to the nhs of trying to find what was wrong would have been tens if not hundreds of thousands as she had multiple invasive, complicated procedures when all that needed to happen was the heel prick test. CMV robbed her of her first few years and still impacts her today. Her deafness is untreatable but could have been prevented if she had been diagnosed at birth. It left me (her mother) unable to return to work as I was her primary caregiver.

Discussion comment:

Given that the heel prick always exists, adding in screening for cmv seems a logical next step in catching ccmv at the earliest stage. It would stop all the investigative searches as the root cause would be known. I think it would be transformative for children with cmv to stop all the invasive tests trying to search for what is wrong. Also as cmv is such a broad infection that causes such a range of issues, narrowing down the cause to cmv means parents and healthcare professionals know the exact issues to look for in that child and they can be treated quickly and effectively

Recommendation comment:

Yea absolutely. It has little to no additional impact on the child but could improve their outcomes enormously whereas currently children are left to develop health issues then treated retrospectively. This is a key step in actively managing cmv

Alternatives comment:

Vaccination of pregnant women

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

My son was born via emergency c section with CMV at 34 weeks gestation. It took 10 days of him being in NICU and doctors scratching their heads for him to be diagnosed after complex testing and screening. He was then referred to XXXX XXXX and XXXX XXXX and started 6 months worth of antivirals. For the first 2 years of his life he was practically in hospital most of the time due to antivirals being a cytotoxic drug and killed his immune system. He is now 10 has severe learning difficulties, autism, adhd, speech and language delay, microcephaly, cysts on his brain and mild hearing loss to name a few. I was never even informed about CMV or the risks in pregnancy whilst pregnant, most physicians also were unaware of it or its complications. My son is one of the lucky ones, he lives a full life and should continue to do so but many babies born with cmv are devastatingly profoundly disabled and live a short live. The UK is one of the very few countries that do not screen for CMV which is just ludicrous!

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

Primary infection in first trimester of pregnancy with twins.

Both babies have cCMV. I didn't know about CMV and how dangerous it could be in pregnancy. Had they not found out about it whilst pregnant, the outcome may have been much more severe.

Recommendation comment:

Yes. Awareness also needs to be raised about how severe this virus can be

---

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

I was diagnosed as having CMV at 28 weeks pregnant and from that point my mental health spiralled. This was an IVF pregnancy, my last embryo which we had genetically tested. My world fell apart. It was a pregnancy following a miscarriage and my CMV diagnosis made it even worse. I was referred to a FM team who scanned me frequently. I chose to wait until baby was born before testing her for the virus. Thankfully she didn't have it.

Evidence Comment:

Even if a baby is asymptomatic, that reassurance at birth that your baby doesn't have it is amazing. If babies are automatically tested, babies who would have no reason to be tested ie CMV not picked up in Mum's blood, if found to have the virus, could be treated with anti virals early, preventing any hearing loss that might only present years down the line.

There needs to be far more awareness of CMV and for midwives to routinely discuss it and for Mum's booking bloods to be tested.

Discussion comment:

Recommendations should be to test

Recommendation comment:

Absolutely should be recommended for the reasons above.

Alternatives comment:

More support once diagnosed ie signposted to an appropriate pathway.

Other comments:

Tell everyone about in nurseries, childcare settings, make it part of basic training, include information in new mum packs, not just a very small detail about what blood tests could be taken. An explanation of treatments for it.

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

This condition has affected me neice who suffers daily due to CMV

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

My son was born with CMV and it would have prepared and helped so much if testing was done during pregnancy as we had no idea until he was born very very sick.

Recommendation comment:

I think screening should be mandatory and I think it wouldn't take much to run extra tests

---

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

My niece has a baby girl who is affected with the condition, it has caused her to be blind, deaf and have physical impairments, she has developmental delays and learning disabilities. All these are caused by CMV and testing earlier could stop these babies having these problems.

Help us stop it NOW

Recommendation comment:

Earlier screening and more is needed

Alternatives comment:

When babies are born with cmv support them

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

cCMV has affecting my little boys hearing we only found out he had this virus due to failing his hearing screening when born. Further investigation has showed and confirmed I had CMV when my 'booking' bloods were done but because they don't test at the beginning it hasn't been confirmed till after pregnancy.

Recommendation comment:

Screening should be recommended for all pregnant woman and the screening should be done throughout the pregnancy. My boy has now lost his hearing due to this virus and up to now that is everything but if we had knowledge or treatment early on then it may have not affected his hearing as much,

Alternatives comment:

Make sure you are tested alongside your regular bloods during pregnancy to see if cmv is detected then if it is for medication to start from inside the womb to try and prevent any long term/life term affects. Even if the meds don't work it's better trying then waiting till it's to late to prevent long term disabilities.

Other comments:

More knowledge around for pregnant woman especially in the first trimester. Extra bloods to be tested for the virus. I had never heard if this virus till now and more people should be aware of the affects the virus can have.

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

I can just say it ruined my life in every single aspect. Besides several miscarriages due to a proven CMV-reactivation chain, I gave birth to a very brain damaged XXXX XXXX due to congenital CMV, without knowing beforehand. It was completely devastating. I am highly educated, I am not religious and originally XXXX XXXX. I would have chosen abortion for sure if I only had known.

I didn't even know of the existence of the virus.

I was a completely healty 33 year woman O had my XXXX XXXX in XXXX XXXX, with two young healthy XXXX XXXX. I sufferd recurrent miscarriages for over a year before birth of my XXXX XXXX, 3 in a row.

I begged my doctors, my gp, the midwife for bloodtests. They didn't took me serious at any point. I was young I should just try again was their response.

Not only did I deliver a very disabled child, I also lost my hearing on my right ear permanently as a professional classical trained singer. Most likely due to varicella zoster virus in combination with pour immunity due to the primair CMV-infection. It gave me many times lunge- and eye-infections. I still suffer a poor health because of it.

Besides my health, I lost my job as a professional singer. It damaged my relation with my partner and my family. It gave my XXXX XXXX a brain hammorage because of all the stress and grief. I don't have a healthy bonding with my child, because if I am really honest, I really don't want to be XXXX XXXX mother. I weep every day for not having the oppurtunity to an abortion at the time.

Evidence Comment:

Yes, I think it is also important to include the link between miscarriage and CMV (Kostova. E. et al. 2023; Schleiss. R. 2024). And it looks like their is also a correlation with the Corona virus, because it attacks the healthy cells the same way. So be carefull when pregnant women contact Corona first. It would make sense if they are at higher risk to contract CMV secundairy.

And last but not least women would like to have a choice, an not only medicine is a treatment. For me abortion is too, don't ignore that.

Offcourse I am pro life, but the life of my XXXX XXXX is very sad, XXXX XXXX is angry most of the times for what XXXX XXXX can not do compared to XXXX XXXX siblings. XXXX XXXX bites, XXXX XXXX yells, cries most of the times. XXXX XXXX has microcefaly, is almost deaf, eyeproblems, XXXX XXXX will never walk, talk, sit as a now 1.5 year child, that is CMV in practice. It is so much more than just this theoretical problem.

Discussion comment:

Yes, check on antibodies if women have a wish to start a family or are suffering miscarriages (under 12 weeks) without having this running in the family. It could help to take procusion in terms of urine and saliva if you are cleaning your baby or if you have two young children under 5 years old. I didn't know the virus at all, I didn't know that you need 70% alcohol to kill it or that it can survive 7 hours on your children's toys, or that I had at least 50% chance without antibodies and due to my astma even more to contract it. It is heartbreaking to think about it. You can pretend it in so many ways why not talk about it.

Recommendation comment:

It would be a real crime against woman and children in general to not recommended it. It is ridiculouss that this is even a discussion, considered the current prevalance, compared with other conditions. Give woman a proper chance to escape this misfortune. We are living in modern times, I still hope to believe this. Listen to the mothers and fathers who are crippled for life because of this innocent but totally misunderstood virus. And just know that countries like Belgium and France give opportunity tot receive Valaciclovir to pregnant women. I think every respectable woman would drive to Belgium if necessary, but it starts by knowing of the virus and the potential risks.

Not to mention it can protect the foetus, without knowing their is a high potential that the liver and spleen are failing to the end of pegnany fighting against the virus. My doctor told me, if my XXXX XXXX would not have come on XXXX XXXX own with 35 weeks, XXXX XXXX would have been stillborn. I don't know what I preferred to be honest, but is not fair tot the child.

When CMV is confirmed. Baby's can be monitored like in Belgium and when they are struggling because of the virus the can be delivered by c-section. Medicine can already be at hand and they don't have to stay in hospital for 2 months like my baby XXXX XXXX. It damaged the bonding between parents and child for good, I can tell you of experience. Is such a shame.

Alternatives comment:

Hang posters, make television commercials, educate doctors, gp's, midwives. Give the virus a name and face, don't hide it. And especially not when pregnant women or women with recurrent miscarriages have longtime symptoms of poor health in general, don't dismiss it to easily. It is already proven that CMV is consistently increase the chance of miscarriage

Other comments:

Just don't take women health for granted, no accaptions made. Give women always a voice concerning cmv-screening. It is our body, our children on the line.

Make an end to this Russian Roulette, because that is actually what is currently. I am just the poor soul pulled the trigger on CMV. Every doctor knew about it, I didn't, but my live is hell and theirs not.

I have to live with the fact that my little XXXX XXXX will die before age of 10 because of bilateral polymicrogyria and epilepsy due to congenital CMV. It is living your worst nightmare.

I don't wish my worst enemie a CMV-child, but I do hope that the whole medical staff, politicians understand in the end a little more of what the cruel reality of CMV implies.

And I really don't believe CMV is the most dangerous, but the current conservative, ignorant, arrogant and womenunfriendly policy most certainly is. My child will not die of CMV. XXXX XXXX will die in near future due to a lack of general interest in the virus

and the motivation of doing something about it. XXXX XXXX and all damaged CMV-children are just collateral damage of a failing system. But please continue this brilliant system. If everyone sleeps well over it, except me....

Give women the oppurtunity to chose for medicine, other modern, more womenfriendly options or even abortion. That's is our right. Don't steal that or our future away from us. Nor steal the future of babies who are in potential healthy, just not protected enough for a very bad virus.

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

My second child was affected by cCMV and with specialist monitoring at XXXX XXXX was shown that his development was severely impaired, especially his brain development.

He was stillborn at 27.5 weeks. He would be 6 years, 10 months, had he lived.

I am affected by his absence and the impact on CMV on a daily basis.

Evidence Comment:

I feel that there is not anywhere near enough information about CMV. Despite it affecting me during my second pregnancy, I'd never heard of the virus, and neither did any of the midwives I came across in my next 2 pregnancies.

CMV should be included in the literature pregnant women are provided with. Education is so important and could save so much heartache for families, and funds longer term for the NHS.

Discussion comment:

As above, significantly more awareness and education required.

Recommendation comment:

Obviously, with my experience, I feel that screening would be beneficial. However, what I think is most important is making sure expectant mothers and midwives are made aware very early on about CMV and how it can be prevented.

Not nearly enough information and education about CMV.

Alternatives comment:

Education.

Other comments:

Education and information.

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

Yes. I was personally affected by congenital CMV, and the impact on both me and my family was significant.

When I was born, my parents had little knowledge and not been told what CMV was at midwife appointments. Because of that lack of information, there was no opportunity for them to take simple hygiene steps that might have reduced the risk. They only learned about CMV after I started showing signs.

My newborn hearing screen was failed, but CMV was not immediately considered. A blood test was taken too late to detect the virus accurately and came back as negative. My parents were reassured, but they were also confused, because they could see that something still wasn't right. Eventually, after more concerns and persistence, a urine PCR test finally confirmed congenital CMV.

That delay caused by gaps in awareness, inconsistent practice and a lack of routine guidance meant that valuable time was lost. I went on to require hearing support, medical follow-up and long-term monitoring that might have been better planned or started earlier if CMV had been recognised straight away.

For my family, the uncertainty was incredibly difficult. They were left trying to understand they didn't know much about, dealing with worry and unanswered questions. They have said many times that the hardest part was not the diagnosis itself, but how long it took to get there and how alone they felt while searching for answers.

The fact that my story is now published by XXXX XXXX reflects how common this experience is for families affected by congenital CMV. My case is not unusual and that is exactly why this consultation matters. Families like mine should not have to learn about CMV after their baby is born and already showing symptoms.

Evidence Comment:

Yes. My experience highlights several limitations in the evidence the UK NSC previously considered when deciding not to recommend screening.

The current evidence review focuses heavily on uncertainties for example, not being able to predict which babies will be seriously affected, limited treatment options, and concerns about overdiagnosis. While these are important considerations, they don't reflect what actually happens to families without screening.

In my case, screening would likely have led to earlier recognition, clearer pathways, and less confusion. Instead, I experienced the consequences of not having screening at all:

CMV was not suspected early, even after an unclear newborn hearing result.

A blood test was taken too late, resulting in a false reassurance.

The lack of systematic screening meant my diagnosis relied on individual clinicians recognising CMV – not a structured pathway.

Valuable time for early monitoring and tailored support was lost.

When the evidence review says screening may cause anxiety or lead to unnecessary tests, it does not fully acknowledge the real anxiety caused by delayed diagnosis, unclear results and parents being left without answers. The absence of screening creates uncertainty too but with fewer safeguards and less support.

The evidence currently emphasises what we don't know. My experience shows what happens when there is no system to catch cases like me early. This gap the practical consequences of not screening is not reflected strongly enough in the review.

The evidence also underestimates how inconsistent awareness is among healthcare professionals. Without screening, families rely on chance: whether a GP or midwife happens to think of CMV. That is not an acceptable or reliable system. Screening, even in a targeted or pilot form, would reduce this inequality and ensure more babies are identified in time to benefit from early intervention.

Discussion comment:

Yes. I believe the current conclusion not recommending screening does not fully reflect the real-world consequences of the absence of screening, which my experience demonstrates clearly.

The review acknowledges uncertainties around predicting outcomes and the limited availability of treatments, but it does not sufficiently consider what happens when there is no screening system at all. In my case, the lack of screening meant that CMV was not identified early, even when there were indicators such as an unclear newborn hearing result. A blood test taken too late produced a false negative, and because screening was not in place, there was no structured pathway to ensure CMV was considered or ruled out correctly.

The conclusion also assumes that screening may not provide enough benefit because not all babies with congenital CMV develop long-term problems. But screening is not only about predicting the future; it is about ensuring early monitoring, consistent pathways, and timely support for those who do develop complications. Without screening, families like mine are left to navigate uncertainty without guidance, and children may miss opportunities for early intervention.

Additionally, the review does not fully address how inconsistent awareness is among healthcare professionals. Screening helps to create structure, consistency and equal access. Without it, diagnosis relies on individual clinicians recognising CMV which often does not happen.

For these reasons, I believe the conclusion should be reconsidered. Even if the Committee is not ready to recommend universal screening, the review should strongly acknowledge the benefits of targeted screening, pilot programmes and clearer pathways. My experience makes clear that the current approach is not enough, and that the risks of continuing without screening are significant.

Recommendation comment:

Yes, CMV screening should absolutely be recommended. As someone personally affected by congenital CMV, I have lived with consequences that could potentially have been reduced if my mum had been offered routine screening during pregnancy. CMV is the leading infectious cause of congenital disability, yet it remains one of the only major risks in pregnancy that parents are not screened for, not informed about, and not monitored for unless symptoms appear too late to change the outcome. Screening would allow earlier diagnosis, which means timely treatment for newborns, more accurate monitoring of the pregnancy, and the ability for parents to make informed decisions rather than being left unprepared. It also aligns with the approach taken for other infections and conditions that are far less common, making the current gap around CMV both inconsistent and difficult to justify. Earlier detection also reduces long-term pressure on health, education, and social care services by enabling earlier support. Families like mine fall through the cracks because CMV is invisible without testing, and the consequences of that silence are lifelong. Routine CMV screening is not just clinically sensible, it is ethically necessary.

Alternatives comment:

One alternative is to introduce mandatory CMV education for all pregnant women at their booking appointment, including simple hygiene measures and clear explanations of how CMV is transmitted. This would ensure that every parent receives accurate information before they are exposed to risk. Another option is to create a national public health campaign targeting both parents and professionals, as awareness among midwives, GPs, and health visitors is currently very low. It may also help to introduce routine CMV training within maternity and paediatric services so that symptoms in both mothers and babies are recognised early.

However, while these alternatives would offer some benefit, they cannot replace the certainty that screening provides. Education and awareness can reduce risk, but they cannot identify infections that are already present, and they do not allow for early treatment or proper monitoring. These options should therefore be seen as additions that support screening rather than alternatives that can replace it.

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

This condition has affected my daughter. It has taken us 7 years to get a diagnosis and has lasting damage to the brain, vision and hearing.

Evidence Comment:

My daughter wasnt tested until she was 6 years old because i have not stopped fighting her corner to better understand why she is deaf and has vision impairment!

She is now 7 and we have just received a diagnosis of CMV.

If they routinely tested, this could have been prevented.

Recommendation comment:

It SHOULD be recommended because it is more common than anyone thinks. It is also linked to ADHD, with 50% patients with CMV also being diagnosed ADHD; this information would be very useful, in getting more appropriate support for education, health and beyond.

Alternatives comment:

Put more information out to the public.

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

I had CMV whilst pregnant with my daughter and did not know till she was 9year old I waited 7year for answers as her hearing had deteriorated and we did not find out she had cmv till 9years old when they retested her heel prick and we were made aware i caught cmv whist pregnant but had no symptoms the doctors told us we were very lucky it had only affected her hearing and did not affect “cerabal palsey syndrome” or any thing else and we were lucky she got to 10years old or older we did not know of this syndrome until the hospital redid her heel prick as she had no other symptoms and we were lucky we got an answer as anytime after 10year they get rid of the heel prick bloods so we just caught it in-time and got our answers ive had another daughter since then but they wont test her for cmv as she has no symptoms but still needs speach therapy like XXXX XXXX did then XXXX XXXX needed hearing aids and they dont seem to want to test grace as she has no other symptoms but neither did XXXX XXXX at time but after her hearing deteriorated she was then tested for CMV without any symptoms i think it’s important to test for cmv even without symptoms as its just part of a heel prick your taking anyway. Cmv is a condition you get whilst pregnant and its like cold/flu you dont go and and see a doctor for it but your not made aware of it either but can be catastrophic to you if it is detected within the babys first 3weeks of life they can be giving Ganciclovir which is a antiviral and gives fewer side affects and better stability but you cant be offered it unless your baby has been diagnosed with CMV there is not enough talk about cmv but it is deadly in children!

Evidence Comment:

Heel prick they do not test for CMV but if they test the heel prick they can test for cmv in a heel prick

Recommendation comment:

Yes i do

Alternatives comment:

Test for cmv in a heel prick ifs not much my midwife tests me for cmv when i am poorly so if she can test regularly why cant you add cmv to a heel prick!

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

Yes my sister was diagnosed with CMV whilst pregnant.

Discussion comment:

I would like to see this implemented as a regular screener for pregnancies

Recommendation comment:

Yes, it's one of the leading causing of hearing loss for children. Early intervention can be key.

Alternatives comment:

More education around this topic and my sister had to do her own research which caused further stress during pregnancy

Other comments:

No

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

A friend

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

Family

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

Yes, affected my friend

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

It effected my niece, when she was pregnant with her baby boy.

Recommendation comment:

Screening should be recommended to pick up any abnormalities.

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

Negatively effected a close friend of mine who went through hell and back throughout her pregnancy to then go on to have a perfectly healthy baby boy.

Evidence Comment:

No

Discussion comment:

No

Recommendation comment:

Yes, the more screening available at a newborn stage the more support parents can get when they most need it.

Alternatives comment:

Educate and support better.

Other comments:

UK National Screening Committee

No.

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

In XXXX XXXX, I became pregnant with my daughter. At our 20-week scan, we were told that she had severe abnormalities and that it was unlikely she would survive to the end of the pregnancy, let alone live outside the womb. She was born at 23 weeks.

The foetal medicine team suspected that congenital CMV was the cause. This was later confirmed through post-mortem examination. Extensive genetic testing showed no underlying genetic conditions; all of my daughter's abnormalities were attributed to congenital CMV. Examination of the placenta confirmed that the infection had been passed from me to my daughter during pregnancy.

This experience has had a profound and lasting impact on me and my family. It is not only the loss itself, but the knowledge that CMV was unknown to us at the time, and that earlier awareness or intervention may have changed our understanding, our decisions, or our preparation. I am filled with regret for my lack of knowledge around this condition, and anger for the lack of awareness that is shared with pregnancy women. The grief I have felt some this situation has been unimaginable, and the thought of any pregnant people, or young children living with the consequences of CMV fills me with sorrow.

Evidence Comment:

From my perspective, the evidence considered by the UK NSC appears to focus heavily on clinical outcomes and screening feasibility, but it has not sufficiently taken into account the lived reality of families affected by congenital CMV. What is often missing from formal reviews is the human cost – the emotional, practical, and long-term developmental impact on children and families when congenital CMV is not identified early.

The limited awareness of CMV among healthcare professionals, teachers, and the general public means that many pregnancies at risk are never flagged until serious damage has already occurred. This gap in awareness is itself evidence that current policy and guidance are not aligning with the real-world needs of families.

In my own experience, congenital CMV caused devastating loss and lifelong consequences that were only understood after the fact, when post-mortem confirmation revealed the extent of the infection. This kind of lived evidence, the stories of loss, missed opportunities for early intervention, and the consequences of a lack of

early awareness, should be given more weight alongside clinical and epidemiological data.

In summary, I believe that the review may have under-represented the importance of awareness, early identification, and family-centred outcomes as part of the evidence base. Including more qualitative data from affected families could deepen understanding of the true impact of CMV and strengthen the case for improved screening and support.

Discussion comment:

I feel that the discussion and conclusions of the review are overly cautious and do not fully reflect the real-world impact of congenital CMV on families. While uncertainty and limitations in the evidence are acknowledged, the recommendations appear to prioritise avoiding potential harms of screening over addressing the very real and devastating harms caused by late or missed diagnosis.

The conclusions do not sufficiently account for the consequences of inaction: babies who are diagnosed only after irreversible damage has occurred, families who are denied information and choice, and parents who learn about CMV only after life-changing loss. These outcomes are not theoretical, they are happening now.

In my view, the review places too little weight on the benefits of early identification, awareness, and parental empowerment. Even where treatment options are limited, early diagnosis can guide monitoring, early intervention, and informed decision-making. The recommendations would be strengthened by a greater emphasis on prevention, awareness, and the lived experiences of affected families, rather than relying so heavily on narrow clinical endpoints.

Overall, I believe the conclusions underestimate the human cost of congenital CMV and the potential benefits of earlier recognition and action.

Recommendation comment:

I believe screening should be recommended because it has the potential to save lives and significantly improve outcomes for children affected by CMV. Early identification allows families and healthcare professionals to monitor, support, and intervene at the earliest possible stage, which can be life-changing for those children who would otherwise be missed.

While it is true that some children identified through screening may never go on to experience serious effects, the benefit of identifying those who are at risk far outweighs this concern. Without screening, children with congenital CMV and CMV can remain undiagnosed until developmental delays or irreversible damage become apparent, by which point opportunities for early support have been lost.

Screening offers the chance to reduce long-term harm, provide families with clarity, and ensure that children who need help receive it at the point when it can make the greatest difference.

Alternatives comment:

There needs to be far greater awareness of CMV, particularly in early pregnancy. Before my own experience, CMV was not something I had ever been informed about or warned of. As a XXXX XXXX teacher, I was in a profession that placed me at higher risk of exposure, yet this was never highlighted to me by healthcare professionals or my workplace.

Had I been aware of CMV, it would have significantly changed my behaviour during early pregnancy – including how I approached close contact at work and how seriously I treated illnesses during my first trimester. That knowledge alone could have altered my level of risk.

Currently, CMV is not routinely discussed with pregnant women, and awareness among schools and professionals working with young children is extremely limited. Improving education and guidance for both healthcare providers and high-risk professions would be a vital step in protecting families and preventing avoidable harm.

A different approach on awareness in the condition could have saved my baby and made immeasurable change to my life.

Other comments:

My primary recommendation is a significant increase in information and awareness about CMV. If routine screening is not currently implemented, then it is essential that parents, educational professionals, and schools are clearly informed about CMV, how it is transmitted, and the serious harm it can cause during pregnancy.

Those working in early years and primary education are at particular risk of exposure, yet CMV is rarely discussed or included in guidance for pregnant staff. Providing clear, accessible information would allow people to make informed choices, take preventative precautions, and recognise when to seek medical advice.

At a minimum, improved education and awareness would help prevent avoidable harm and ensure that families are not learning about CMV only after devastating outcomes have already occurred.

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

Yes, I had a baby in XXXX XXXX, luckily we knew he had Ccmv prior to him being born as we had complications in my pregnancy and it came to our attention that I

caught cmv for the first time in my pregnancy with XXXX XXXX (my son). He was able to be treated for this with antivirals on day 3 of his life to stop it progressing hopefully, and a lot of tests to check his health and how this had impacted him. Currently XXXX XXXX's only impact his moderate to severe hearing loss in his left ear but is being monitored regularly. I have seen how this condition can impact families and children, especially when it isn't diagnosed / missed for years and it's too late.

Recommendation comment:

I think screening for this for newborns should absolutely happen. This could save so many families from heartbreak and constant worrying. If a baby is diagnosed at least treatment can be started for that child to minimise further issues which may arise should the treatment not be started.

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

As someone who had CMV during my second pregnancy and all the stress, unknown and the devastating effects of CMV, I can't believe that a simple screening progress hasn't and won't be implemented. It's so simple to treat if known about. Please reconsider and make this screening a national requirement

Evidence Comment:

As someone who had CMV during my second pregnancy and all the stress, unknown and the devastating effects of CMV, I can't believe that a simple screening progress hasn't and won't be implemented. It's so simple to treat if known about. Please reconsider and make this screening a national requirement

Recommendation comment:

As someone who had CMV during my second pregnancy and all the stress, unknown and the devastating effects of CMV, I can't believe that a simple screening progress hasn't and won't be implemented. It's so simple to treat if known about. Please reconsider and make this screening a national requirement

---

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

Yes

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

It effected my niece, when she was pregnant with her baby boy.

Recommendation comment:

Screening should be recommended to pick up any abnormalities.

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

Yes family freinds

Evidence Comment:

Yes

Discussion comment:

No

Recommendation comment:

Yes definitely

Alternatives comment:

Ok

Other comments:

Get early screenings going

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

Yes I caught CMV in my first trimester and had to undergo lots of tests and uncertainties during my pregnancy.

My baby tested negative upon being born. However from learning about the condition I would like to see it in used in newborn screening.

Recommendation comment:

Should be.

It has irreversible damage by the time it’s caught in any cases

---

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

No but people close to me

Evidence Comment:

No

Discussion comment:

No

Recommendation comment:

Should be recommended to help mothers further down the line

Alternatives comment:

Screening tests similar to

Breast screening appointments

Other comments:

No

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

My daughter was born with congenital CMV and thanksfully no signs of it have been showed so far, but the surprise of the news during pregnancy, and the lack of awareness and information from most of the people made everything much more difficult and scary.

Evidence Comment:

N/A

Discussion comment:

I still believe that even though there are not a lot of data that shows that all kids who get CMV can show symptoms or that is not yet a treatment that can assure that the early detection will change the end result, it is important to make parents to be aware about the virus so they can take the right cautions to prevent getting it during the pregnancy.

On top of this, it is also important to have enough information for those people who have to go through it so the journey does not feel so lonely.

Recommendation comment:

It should be recommended for most of the points I have highlighted above

Alternatives comment:

At least with information during the pregnancy or even before.

General awareness to the public as well could be really really helpful.

Other comments:

N/A

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

My daughter went through a v difficult pregnancy being told they baby may die or be affected by CMv

There should be widespread education on this condition and research into how to manage and work with those impacted as well as prevention

Recommendation comment:

I believe screening should be included as it can save lives and disability with simple interventions

---

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

My child

Evidence Comment:

Congenital cmv confirmed with brain imaging and calcification

Discussion comment:

Testing during pregnancy should be mandatory. Simple screening could avoid so many children from being disabled. Pregnant women undergo many tests, adding one more to help in avoiding life altering conditions should be mandatory. Tested or not they forced COVID vaccine on many people. Test pregnant women for the leading cause in disability in unborn children.

Recommendation comment:

Screening should be mandatory. Testing during pregnancy should be mandatory. Simple screening could avoid so many children from being disabled. Pregnant women undergo many tests, adding one more to help in avoiding life altering conditions should be mandatory. Tested or not they forced COVID vaccine on many people. Test pregnant women for the leading cause in disability in unborn children.

Alternatives comment:

Test the blood give them a vaccine against this virus.

Other comments:

Test pregnant women for this virus and treat it!

Name: XXXX XXXX

Affected Comment:

It has impacted my friends son. He has a life long disability as a result of CMV (profoundly deaf) his family and professionals were unaware of CMV when he was born until he was identified as profoundly deaf, his heel prick card was then retested for CMV when investigating why he was deaf. He tested positive for CMV on his heel prick card 4 years after the test was done. If CMV was part of the heel prick card at birth Tom could have received treatment to reduce the impact that CMV had on him.

Recommendation comment:

Yes, knowing someone who is profoundly deaf from CMV could be different if he was tested at birth he could have received treatment.

Alternatives comment:

Yes

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

My son was born with cCMV and is profoundly deaf, with brain abnormalities and learning delays.

Recommendation comment:

Gathering a large dataset of cCMV status at birth will likely reveal that many seemingly asymptomatic cases are actually impactful in later childhood/life (eg autism/ADHD). For those classed as symptomatic the infection is early in pregnancy and impacts neuronal outgrowth in a prominent fashion with clearly observable outcomes at birth, when infected later in pregnancy symptoms are more subtle and may only be noticeable over time, at which point it is impossible to trace it back to cCMV infection.

If it could be shown that cCMV harms a larger number of children, with a bigger long-term societal impact, then this adds weight to the need for a vaccine and education about CMV transition.

Alternatives comment:

I can appreciate that screening all new borns may not be practical, but a more focused screening effort should be enforced. All babies who fail their newborn hearing screen should be tested. This is currently a postcode lottery. This approach would reduce the burden of testing on the NHS but allow more families to access support, prioritised follow-up hearing tests and anti-viral treatment ASAP following birth should their child be found to be cCMV positive.

There should be much more prominent guidance and education of all women, but especially pregnant women, into cCMV and how to avoid it's transmission. The adjustments to a pregnant womans life are minimal, no worse then many other recommendations that are made, there is no reason for this not to be strongly shared by midwives but also to all women of a child bearing age. I feel greatly let down that I never knew about cCMV during my pregnancy.

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

Families deserve to know and understand whether cCMV is in play, when it's a leading cause of childhood disability. The sooner we pick up on it, the more we can support frantic parents with the best outcomes. Also, with a declining birth rate, each child is precious.

Evidence Comment:

I'm only a lay person, but the time and testing and stress incurred later in childhood when trying to diagnose cCMV could be much minimised by screening. Think of the cost: emotional, temporal, and financial of late diagnosis.

Recommendation comment:

Absolutely should be recommended for the reasons above.

Alternatives comment:

I think screening at birth is the easiest and most uncomplicated way to catch cCMV. If cCMV is detected after 3 weeks then there is uncertainty whether it was congenital (antenatal infection), perinatal or acquired (postnatal infection) therefore does not confirm cCMV infection. This could be very helpful in guiding the management of these babies that are particularly vulnerable to symptomatic postnatal infection.

Other comments:

Educate people more about this, including parents and pregnant people.

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

My sister was diagnosed with CMV during the latter stages of pregnancy. My niece was subsequently diagnosed at birth and now lives with unilateral deafness as a result of the virus.

Evidence Comment:

N/A

Discussion comment:

N/A

Recommendation comment:

Screening should absolutely be recommended. Not enough people are aware of CMV and the affect it can have on children. Nor are they aware of the steps they can take to mitigate the risks of infection during pregnancy.

Alternatives comment:

Midwives should be making their patients aware of the CMV and its associated risks.

Other comments:

N/A

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

Our Granddaughter was born prematurely and was diagnosed with CMV, as a result she is profoundly deaf in one ear

---

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

Our Granddaughter was born at 33 weeks and diagnosed with having CMV. She has thrived and doing well but is totally deaf in one of her ears. She is now 6 years old. She has a hearing device to help her and supported at her School.

Recommendation comment:

I definitely think screening for CMV should be given to pregnant mums as so important. I believe this screening happens already in Switzerland.

Other comments:

Screening for CMV is vital.

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

Yes, my grandson XXXX XXXX, who will be 12 this year, was born with cCMV. He is very severely affected. His profound deafness was fairly swiftly identified but there

was a delay of many months before it was established that he had cCMV, despite the fact that he was failing many milestones.

Evidence Comment:

1. Evidence such as the experience of my son & daughter-in-law.

2. XXXX XXXX was their second child. His elder brother was 3 when he was born and attended daycare nursery school from an early age. He also used a dummy. There was no evidence provided of the obvious connection between cCMV and familial daycare where everything goes into a young child's mouth!

3. There was no evidence provided of the lack of GP awareness of cCMV and the lack of advice to parents of a young sibling to take avoiding infection action whilst pregnant – eg not to finish their young child's meal, not to kiss them on the mouth and to thoroughly wash their hands after every interaction in case their older child has co picked up CMV.

Discussion comment:

The conclusions underestimate the number of families affected by CMV. We understand that CMV is more common than Down's Syndrome, that 1 in 4 babies identifying with CMV may become seriously affected.

Recommendation comment:

Screening should be recommended because the cost and support implications of caring for a cCMV baby are enormous, particularly as they get older.

Alternatives comment:

cCMV is a barely known serious condition. As stated above, GPs and midwives should alert pregnant women to take extra care, especially if there are other very young children in the family. Daycare nurseries also seem to be unaware of the risks of passing on CMV through bodily fluids – they understand that thru need to wash their hands each time after changing a baby's nappy, but not why. And they do not understand the risks of everything, eg toys etc, being put in the mouth.

Other comments:

GPS and midwives need better education to understand CMV and cCMV. There needs to be greater publicity of the condition so that mothers understand the risks before it is too late.

Whenever we tell people about our grandson's cCMV and the seriousness of its effect on him, they admit they have never heard of CMV. But they all know about Down's Syndrome.

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

This condition has effected a dear family friend & their child. This condition can be better avoided/managed with an effective screening programme.

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

Yes. Congenital CMV affected our daughter at birth.

We were fortunate that a highly skilled consultant recognised the signs of CMV immediately following a difficult premature delivery. Our daughter spent two months in intensive care and required medication and ongoing medical support. Early recognition and treatment helped to limit the impact of CMV, but she was still left with permanent hearing loss.

Had CMV not been identified so quickly, the consequences could have been far more severe. Many families are not as fortunate and only receive a diagnosis after irreversible damage has occurred.

This experience underlines the importance of antenatal testing and improved awareness. CMV testing during pregnancy is simple and would allow earlier diagnosis, better preparation, and in some cases prevention of harm. The NHS should reconsider its approach and ensure women are offered CMV testing in pregnancy to reduce avoidable lifelong impacts on children and families.

Evidence Comment:

The UK NSC review considers a large and relevant body of evidence, but its interpretation places too much weight on the absence of large UK screening trials and not enough on the clear clinical benefits of early detection.

There is now strong evidence that antenatal CMV screening can accurately identify primary maternal infection and that early treatment with valaciclovir significantly reduces fetal transmission. This represents a major shift from earlier reviews and should be given greater importance.

The review also underestimates the harm caused by not screening. Many children with congenital CMV are diagnosed only after irreversible damage has occurred. Earlier identification would improve care, monitoring, parental counselling, and outcomes, even where transmission cannot be prevented.

While screening may not detect all CMV infections, it would prevent a substantial proportion of the most severe cases, which are linked to early primary infection. This public health benefit is not adequately reflected.

Overall, no key evidence appears to be missing, but the weight given to existing evidence underplays the life-changing benefits of early CMV screening and intervention.

Discussion comment:

The discussion and conclusions are cautious to the point of being overly conservative and do not fully reflect the strength or implications of the evidence presented. In particular, the availability of effective antenatal treatment and accurate screening tests represents a meaningful shift that is not adequately translated into the recommendations.

The review focuses heavily on uncertainty and potential harms, while giving insufficient weight to the very real and well-documented harms of delayed or missed diagnosis. The conclusion does not adequately reflect the benefits of earlier identification for clinical management, parental counselling, and improved outcomes.

As a result, the recommendations underestimate the potential public health and individual benefits of CMV screening. A more balanced conclusion would acknowledge that waiting for perfect evidence risks ongoing, preventable harm to children and families.

Recommendation comment:

Yes, CMV screening should be recommended.

There is now strong evidence that both antenatal and newborn CMV screening tests are accurate, safe, and feasible, and that early identification leads to improved clinical management and outcomes. Importantly, antenatal screening enables early treatment with valaciclovir, which has been shown to significantly reduce fetal transmission, directly preventing harm.

Failing to screen means many children are diagnosed only after irreversible damage, such as hearing loss or neurodevelopmental impairment, has already occurred. Even when screening does not prevent infection, early diagnosis improves monitoring, timely intervention, and parental counselling.

While no screening programme will detect every case, preventing even a proportion of severe and lifelong disabilities represents a clear public health benefit. On this

basis, the balance of benefit versus harm supports recommending CMV screening rather than continuing the current approach of late and inconsistent diagnosis.

Alternatives comment:

If a full screening programme is not introduced, the NHS and government should still take stronger action to reduce harm from congenital CMV.

This should include routine education for pregnant women and healthcare professionals about CMV transmission and prevention, universal access to CMV testing when requested in pregnancy, and clear national clinical pathways for investigation and management of suspected CMV.

Targeted newborn testing (for example following failed hearing screening or maternal infection) should be standardised nationwide, with guaranteed rapid access to confirmatory testing, antiviral treatment where indicated, and long-term hearing and developmental follow-up.

In addition, improved data collection, national surveillance, and investment in research would help address current evidence gaps. However, these measures should be seen as complementary to, not a substitute for, screening, as they still rely on cases being recognised in time to make a meaningful difference.

Other comments:

Yes. In addition to reconsidering screening, there should be a national focus on CMV education, early testing, and consistent care pathways.

This should include mandatory training for midwives, obstetricians, neonatologists and GPs on CMV recognition, prevention, and management; clear guidance ensuring timely access to CMV testing in pregnancy and after birth; and guaranteed follow-up services for affected children, including hearing, developmental, and family support.

Parents should be given clear, accessible information about CMV risks and symptoms, and national data collection should be improved to better understand outcomes and inform future policy.

Taken together, these measures would reduce avoidable harm, improve equity of care, and ensure that children and families affected by CMV receive timely and appropriate support.

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

My granddaughter was born with this condition.

Recommendation comment:

I feel some level of screening should be made available to pregnant women and/or they should be made aware of the virus as I had never heard of it, and neither had my family.

Alternatives comment:

There should be more training and understanding of the virus for midwives during their degree course as it is not discussed in depth enough.

Other comments:

Far more awareness via social media, GP notice boards, hospital notice boards, discussion with midwives during early assessments.

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

My grandaughter was born with this condition and is now partially deaf.

Evidence Comment:

No

Discussion comment:

No

Recommendation comment:

Yes it should to try to alleviate the issues.

Alternatives comment:

More training for midwives to create awareness for parents.

Other comments:

More information via social media, noticeboards etc.

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

Yes, my niece

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

My great niece has this condition which led to premature birth and consequently hearing loss (partial)

Recommendation comment:

It should be recommended. Something so simple and innocuous to carry out would have saved a lot of anxiety for my niece and given her the knowledge of what she was dealing with earlier

---

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

This affected my best friend and her second born child.

Recommendation comment:

I think it should be recommended. A simple step which could give people the opportunity to make a more informed decision.

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

CMV being tested on the newborn bloodspot test is up for consultation this year, so please consider this as it would have saved my friends granddaughters deafness.

Evidence Comment:

CMV being tested on the newborn bloodspot test is up for consultation this year, so please consider this as it would have saved my friends granddaughters deafness.

Recommendation comment:

CMV being tested on the newborn bloodspot test is up for consultation this year, so please consider this as it would have saved my friends granddaughters deafness.

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

This seriously changed the life of our best friends Granddaughter XXXX XXXX so screening would be an important issue for future generations.

Recommendation comment:

Screening should be recommended to allow families to accept and plan for the condition.

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

This condition effected a friends granddaughter.

Evidence Comment:

I feel that this should be reviewed.

Discussion comment:

No

Recommendation comment:

Definitely should be reviewed to cover this along with many other conditions

Alternatives comment:

Screening is the best way forward in my opinion

Other comments:

No

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

This affected a friends grand daughter who has been left deaf in one ear

Evidence Comment:

Dont know

Discussion comment:

No

Recommendation comment:

Yes most definitely be recommended

Alternatives comment:

More publicity

Other comments:

None, but Im not a professional working for the NHS

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

Yes affected very close friends daughter. A simple test could stop this. It should be a mandatory test.

Evidence Comment:

No

Discussion comment:

No

Recommendation comment:

No

Alternatives comment:

No

Other comments:

No

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

My daughter has congenital CMV and is profoundly deaf in one ear as a result. In our particular situation I had raised white blood cell count during pregnancy which was dismissed as worthy of investigation by an obstetrician when referred by

midwives. I believe that had appropriate caution been exercised a CMV diagnoses would have been given and that there would potentially have been treatment options available to me which could have saved my daughter's hearing.

Furthermore, at birth my daughter presented with several symptoms including being small for dates and having the 'blueberry muffin' rash. Again, the midwives that delivered her noticed this and referred her to a paediatrician who attended some hours later and dismissed it as being due to a fast delivery. I find it terrifying that a paediatrician can be so ignorant of the symptoms of a virus which is the leading cause of childhood hearing loss and a major cause of childhood disability. The following day she failed her newborn hearing test which was again put down to the fast delivery. The lack of joined up thinking, continuity of care and follow up meant that my daughter was not screened for CMV until some weeks later after she was diagnosed as profoundly deaf. This delay meant that as she was around 12 weeks by this time that our options had been removed; we had not fallen within the critical 28 day window and therefore anti virals were not available to us.

I felt extremely angry and let down by the NHS and the individuals concerned and I feel passionately that newborn screening, like we happily taken on for so many other, less common diseases would stop other families from finding themselves in this terrible situation. At the very least targeted screening should be offered across all NHS trusts in the event that a baby fails its newborn hearing test. The postcode lottery in which we currently live is in the simplest terms unfair.

Evidence Comment:

I feel that the views of families is important evidence that was omitted from the review. The plain English summary states 'More studies comparing cCMV screening to standard medical practice without screening are needed to confirm exactly how children might benefit from screening.' However surely a parent's view of how their children did benefit or may have benefitted should also be considered? Who is better placed to make that assessment than a parent or primary caregiver?

Discussion comment:

It is my belief that no parent or primary caregiver of a child with cCMV would agree with the conclusion that there is 'no conclusive evidence that newborn screening for cCMV will be beneficial.' The conclusive evidence for those families effected is their baby or child living with the impacts of a late or missed diagnosis and the huge impact this has on the family lives.

Recommendation comment:

Per my first answer, having been through the awful rollercoaster of emotions of experiencing a late diagnosis of cCMV it is absolutely imperative that the current system changes. Babies and their families continue to be let down by maintaining the status quo and that is not good enough.

I believe that the benefits of screening far outweigh the risks of causing anxiety to the families of asymptomatic babies. Knowledge is power. The anxiety can be managed by the professionals administering screening and delivering results and also through education about CMV to the general public. Not knowing, or finding out too late is worse. That harm grossly outweighs anything else. Families deserve options, to be able to make the right choices for their child, to choose (or not) to have anti virals but in too many instances under the current system the choice is being made for them through in action and ignorance of healthcare professionals. It is also my belief that, should universal screening be implemented, after a period of adjustment, society would get used to it just as we have other screening tests that are offered to pregnant women such as HIV, syphilis and Down syndrome.

Failing a universal screening programme targeted screening must become the norm. I do not understand why, when a baby fails its hearing test a CMV screening test isn't triggered? I also cannot comprehend why some NHS trusts are doing this and others aren't. How are we continuing to live in such an inequitable society? Why is a baby in one postcode worthy of a screening test, diagnosis and potential treatment while a baby living a couple of streets away is not? How can that be?

Alternatives comment:

Education! I cannot fathom why there are not posters in every antenatal waiting room, doctor's surgery, nursery school etc with simple guidance about CMV. It is so very common yet very few people have heard of it until their baby is diagnosed. That is not good enough. As a pregnant person you spend hours and hours in waiting rooms staring at posters about all manner of things from domestic violence to foetal alcohol syndrome; why is something as important as CMV not given the same attention?

Furthermore there are educational films about CMV and they should be included on the roll of films you see in waiting rooms too. It isn't any more or less scary than watching something about SIDS and resuscitation as you wait for an antenatal scan yet the simple guidance on how best to keep yourself safe from CMV could make all the difference.

If the government could partner with the British charity CMV Action and/ or provide funding to facilitate an awareness campaign the situation could be dramatically improved. CMV Action work tirelessly to try and support families effected, spread awareness, educate the population and healthcare professionals but they are a small charity and their reach is limited by means. They could be a fantastic asset in the fight against CMV.

Other comments:

Similar to my point above if the NHS could work with CMV Action on a public health education campaign it would be a good start as we wait for screening and a vaccine.

UK National Screening Committee

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

My son had cCMV. When my bloods were revisited from during my pregnancy, they showed that I had CMV and it was reactivated during my pregnancy. My start to motherhood was very complicated and my sons care continues to be affected by this reality. We have also struggled with the lack of information and training in the care system. Looking back on the neglect and misinformation from my last month of pregnancy is frightening. Only once we were with specialists we had information and help. My sons stop in growth during the pregnancy, jaundice, and failed hearing test was ignored by professional after professional. My son is bilaterally profoundly deaf because of CMV. We have had to learn BSL without any support.

Evidence Comment:

Unable to comment on this.

Discussion comment:

There is very little awareness of cCMV. And when you learn about it, there is too little information. There are so many tests, warnings and recommendations when expecting a baby. CMV should at least be mentioned and warnings around the impact of cCMV should be shared. Best practice should include guiding pregnant women on CMV preventative measures (wash hands, changing nappies, no sharing food etc).

Recommendation comment:

Definitely. Screening plays such a big role in helping expectant mothers feeling like they are in the know, being proactive, and staying informed. We are given the options with trust in the system letting us know of all that is important and available for us. I personally also did it to help the system follow best practice and supply data collection that helps to form a healthy health care system. I trusted the professionals to exhaust all options. When everything was on track screening would have been good. It was extremely damaging when I was in the hospital for 6 days post emergency c-section and no-one mentioned cCMV or testing for it. Professionals saw us and said they were trying to understand what has happened. cCMV was clearly not even on their radar and would maybe be if it is part of screening.

Alternatives comment:

More help and information around cCMV and the families affected by it. This is needed no matter the outcome of this process. The lack of information makes it an even scarier and lonelier.

If not a screening for all pregnant woman, at least testing offered in the instance of any concerns.

Other comments:

I had two audiologists in the hospital ignore the failed tests he had. A month later I had another audiologist in a follow up appointment ask if she can give him a swab as a start to see why he is deaf. Are these issues being picked up too late and not in the correct setting? I was kept in the hospital for 6 days and not swabbed there. Antivirals are meant to be given within 4 weeks of life, my son was only swabbed at 4 weeks old. Surely a failed newborn hearing screening at birth should trigger a CMV screening / swab.

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

My granddaughter was born with cCMV in XXXX XXXX. She is profoundly deaf in both ears. My son and his wife plus both sets of grandparents were devastated when she was diagnosed at 6 weeks old after failing her hearing tests.

My son and daughter-in-law will not discuss CMV at all as I think they feel guilty, particulary my XXXX XXXX, who is a GP. Other than being deaf, my granddaughter appears healthy in all other aspects, so they have blanked out CMV. They get angry if I mention CMV. I am the only family member receiving information from CMV action.

My granddaughter had bilateral cochlear implants at 12 months old and now is understanding and starting to speak, when wearing her processors. We call her our medical miracle. She has great support, but I personally still find it heartbreaking as she will always have this disability that could perhaps have been discovered and diagnosed earlier.

The whole extended family have been impacted and are aware of CMV.

Evidence Comment:

Retest of hearing should have been sooner, then cCMV would have been detected earlier so anti-virals could have commenced sooner

Discussion comment:

Screening should be a standard test for pregnant mothers and new born babies.

Recommendation comment:

Screening should be recommended, particularly for mothers who may be more at risk, such as other children particularly of nursery age, and professions/vocations that are more high risk to exposure to CMV such as medical, nursery employees, teachers etc.

Alternatives comment:

Ensure the child is monitored regularly

Other comments:

Include information about CMV in all literature issued to pregnant mothers. Posters in GP surgeries and anti-natal groups. Include a session about CMV in all anti-natal classes.

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

Primarily this disease affected my daughter but it has understandably affected us as a family.

Evidence Comment:

I think it would be interesting for the increased number of children with learning difficulties to have their newborn blood spot test checked, to see if CMV was present at birth.

Also, it baffles me that we screen for 10 rare but serious conditions at birth in the UK, yet the rates for being with CMV, are drastically higher than the majority of all the tested conditions.

Maple Syrup Urine – 1 in 116,000 infants in the UK

PKU – 1 in 10,000 infants in the UK

MCAAD – 1 in 8000 infants in the UK

CF – 1 in 2500 infants in the UK

Sickle cell – 1 in 2000 infants in the UK

CMV – 1 in 100-200 infants in the UK

Discussion comment:

I agree that this needs to be looked at urgently & the many different ways that CMV can be tested to be reviewed.

This could make a huge difference to so many families in the UK & potentially, worldwide.

Recommendation comment:

I think screening of this awful condition should become a recommendation. We have seen first hand how this condition can affect our children & it's a terrible thing to go through. I appreciate that many children will have cCMV, be asymptomatic & go on to live completely normal lives but there is a huge number that this does not apply to. The parents of these children may not realise they're child has CMV until it's too late.

Alternatives comment:

Information sharing! I was a practising Midwife at the time my daughter contracted this disease & myself & the vast majority of my colleagues had never heard of this disease. The spread from children to parents & therefore the fetus can be stopped so easily if we just advised patients on this. It's shocking how little people know about this disease, considering how many newborns (that we know of) are born with it each year.

Other comments:

Please, please, please can something be done about this. If not newborn screening or screening mothers, then giving the general public advice on how to prevent the spread of this disease. It is so simple to put a stop to the spread of it, if only people knew how.

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

It has affected the family of a friend.

I also work with families who are impacted by cCMV.

Evidence Comment:

It feels like a very small sample?

How much were families directly impacted by cCMV part of the report?

Recommendation comment:

SHOULD be recommended. Ideally for everyone, but at a minimum, to screen for those who have never had CMV and are at primary risk.

I think that there is screening for so many other things in pregnancy, I just don't understand why this isn't routine too, and it is in other countries. Even many health professionals lack understanding of CMV, so clearly babies are not being diagnosed, and then not getting treatment in time.

we know it's a bigger risk for mums who have never had CMV before, and we know that the third trimester is a higher risk to pass the infection to baby if mum has it. This for me highlights the babies most at risk.

Alternatives comment:

There needs to be more support for charities like CMV Action working to highlight the condition and preventative care. Awareness is key.

There needs to be more training for health professionals and care professionals.

Other comments:

There hasn't been a huge improvement in the stats so far, so something has to change! can't keep doing the same.....

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

It has effected a good friend of mines granddaughter.

Recommendation comment:

I feel yes screening is vital to confirm early diagnosis.

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

yes my son who was born in XXXX XXXX was diagnosed with CMV 6 months after birth. No guthrie testing was done until this time and it was done in XXXX XXXX via XXXX XXXX, even though he showed the classic signs of CMV, This elapse of time was crucial as he got CMV 2 weeks antenatally we think and early intervention could have had a life changing impact had birth screening occurred. Employment, communication, epilepsy, hearing (he has a cochlear implants but received them late nearly 4 years old) and balance are major impacts

Evidence Comment:

Totally disagree about not doing birth screening for CMV. I am only a lay person but it has to be worth undertaking a cost benefit analysis of doing and not doing it by reference to the social and health costs of treating CMV immediately post natally and not.

Ideally ante natal screening could be done but timing is an issue as if with my son he is thought not to have got it until week 38 of the pregnancy conducted too early it may not pick it up.

Not doing it birth when there is the medical ability to do so and when treatment in the first few weeks can be so effective makes no sense to the point of being reckless with paediatric health.

Discussion comment:

‘do not screen’ recommendation for birth screening is scientifically obtuse and should be undertaken. Recognise there are cost implications but these should be juxtaposed with an analysis of the costs of CMV to society.

Recommendation comment:

yes absolutely

the ability to treat CMV with antivirals with 2-3 weeks of birth and arrest its life changing impacts, such as in my sons case deafness and targetting and removing funcitonality of cochlear, vestibular receptors and calcification leading to lifelong epilepsy would mitigate a very large social and personal cost

Alternatives comment:

if not treated within 2- 3 weeks of birth you are not so much much treating the condition as the nature of disability it has engendered be it deafness, blindness,

palsy or other disabilities. If not treated in this 2-3 week window the damage is largely done

The USA and Canada and some Eu Member states have adpoted birth screening for CMV. It sort of confirms the UK's minimisation of child health with us sitting in the slow lane on this compared to countries we like to perceive as health care peers.

Other comments:

. Birth screen

. Conduct research into the cost of the virus to the health services/public purse

. conduct a screening trial to monitor impact and effectiveness of screeing

. Consult other national screening committees and pool research and/or research costs and apply learnings from elsewhere

. Support and invite organisations such as cmv action – www.cmvaction.org to contribute as they understand the lifecycle and consequences of the virus and its impact with their relationship with families and parents of CMV affected children

---

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

My daughter was born with cCMV. This was my 3rd Midwife led care pregnancy. I tested positive for COVID in the pregnancy and was then offered growth scans as a precaution. Ironically, at 28 weeks pregnant, I stepped away from my clinical role as an NHS midwife to shield from covid. My pregnancy continued normally and I delivered my daughter at 41 weeks. XXXX XXXX showed signs on cCMV soon after birth. Her first urine was bright yellow/green, she had peticae over her face and shoulders and developed pathological jaundice. We spent the first 24hrs of her life in children's a&e. Soon after we arrived home, she stopped breathing and she was admitted to hospital. 8 days later, she was diagnosed with cCMV. She was commenced on antiviral medication. She has been diagnosed with severe unilateral hearing loss, widespread brain damage leading to a intellectual disability, autism, physical difficulties and is under investigation for CVI.

XXXX XXXX has been severely impacted by cCMV but I often wonder 'what if' she wasn't tested early enough and what if she didn't receive the antivirals. Her disabilities may have been worse and her 'golden ticket' diagnosis that has given her access to services without a fight. Things would have been very different.

Recommendation comment:

Screening should be recommended. As the leading cause of childhood disability, how can we not give these children and their families the gift of early intervention that only that ‘golden ticket’ diagnosis can offer.

CMV has complicated and altered our lives, including that of our 2 other children. It has taken away the little girl that was developing so perfectly inside me before CMV took her from us. We are one of the lucky ones, our daughter is alive and happy. However, without diagnosis, treatment and early intervention would not have occured. Our lives have been impacted hugely but I can not begin to imagine the difficulty journey we would have been on without that diagnosis at 8 days old.

Alternatives comment:

As a midwife of 13 years, I myself was unaware of the risks of CMV. In the last 4 years I have educated my colleagues on cmv and I am yet to find one that knew the dangers and how it is spread. If Midwives don’t know then pregnant women aren’t being educated. At a community booking appointment, women are given advice to stay away from sheep, cat poo, Mr whippy ice cream but nobody is speaking about reducing the risks of viruses, especially those with toddlers at home. I have also spoken to a fetal medicine consultant about our story and her response to me “where on earth did you pick that up?” If we can’t do better at educating pregnant women, then at least we can support those affected to access services and treatment in an attempt to hold on to some of the child they were creating inutero before CMV harmed them.

Other comments:

Educate

Screen.

Diagnose

Treat

Early intervention

Support

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

Our grand daughter was born in XXXX XXXX and was found to have hearing problems due to congenital CMV. Our daughter in law worked as an infant schoolteacher at the time of her pregnancy and likely caught the virus at work. XXXX XXXX is now nearly 4 and the 20% hearing that she had in one ear was wiped out almost over night last year. The worry of where this monstrous virus will strike next is overwhelming. None of us had heard of CMV before it struck our family. Health workers and pregnant women and their families that we speak to have not heard of it. The points you raise against screening sound valid but to us just highlight the amount of work that needs to be done to combat this life changing infection. Screening would help save some children but it would also elevate awareness and make it more appealing as a research subject. Please change your minds.

Evidence Comment:

Not qualified to comment

Discussion comment:

Please recommend screening for CMV

Recommendation comment:

Screening should be recommended to ensure that early treatment takes place appropriately and to raise awareness amongst the public of the risks so that people could be more vigilant.

Alternatives comment:

More determined research into treatment

Other comments:

Repeated failures at the diagnostic stage of our granddaughter's infection meant that opportunities for early treatment were missed. If the condition was taken more seriously this would likely not have happened.

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

I strongly support the introduction of universal newborn screening for congenital cytomegalovirus (cCMV).

My son was officially diagnosed with cCMV shortly before his second birthday. By that point, it was far too late for any antiviral treatment that might have reduced the severity of his outcomes. As a result of cCMV, he has a profound permanent disability, profound bilateral deafness, and specific learning difficulties (including dyscalculia which has known link to CMV), which impact his daily life and future independence. These are lifelong consequences of an infection that went undetected and unmanaged.

As parents, we were completely powerless to prevent or mitigate this outcome because we were never given the necessary information. During my pregnancy, I was not informed about CMV at all. I was not told that it is a common virus, that it poses a serious risk to unborn babies, or that simple hygiene measures, such as careful handwashing and avoiding saliva contact from young children, can significantly reduce the risk of transmission. Had we been informed, we would have taken every possible precaution. This has caused great emotional trauma since his diagnosis, as I personally feel and live with the guilt of passing the virus to my son which has had such a direct impact on him.

Sixteen years on, it is deeply distressing to hear families and parents still asking the same question: why does nobody talk about CMV? Despite increased awareness in some professional circles, the reality for expectant parents has not meaningfully changed. Lack of information continues to result in preventable harm.

Universal newborn screening for cCMV would allow for early diagnosis, timely antiviral treatment where appropriate, and early monitoring and intervention for hearing loss and developmental needs. We didn’t have this opportunity- our son was never given this chance. He lives with the consequences of CMV every day. It impacts him not just in practical terms but also affects his emotional health and wellbeing as he navigates a predominantly hearing world with his hearing and communication difficulties caused by CMV. Even as a now young adult he feels all too often the impact his disability has on him, particularly as he strives to become more independent. There are often real frustrations inextricably linked with CMV and the lasting impact it has had on him. Screening, alongside proper antenatal education about CMV, would give families knowledge, choice, and the chance to act. That opportunity was not given to us, and it should not continue to be denied to others.

Evidence Comment:

I welcome the acknowledgement in the review of the impact congenital CMV can have on children and families. However, I believe the discussion and conclusions underestimate both the consequences of delayed diagnosis and the ongoing failure to provide parents with information and also opportunity for intervention.

The previous review places considerable emphasis on uncertainty, potential harms of screening, and implementation challenges, yet gives insufficient reasoning to the harms of not screening. My own and my son's experience demonstrates these harms clearly. Because my son was diagnosed just before his second birthday, he was ineligible for antiviral treatment and missed the opportunity for early monitoring and intervention. The result is permanent, life-long disability that affects every aspect of his daily life. Unfortunately, we are not alone and so many other children, adults, families and parents have to live with such consequences everyday.

While the review recognises the lack of awareness of CMV among pregnant women, its recommendations do not adequately address this gap. Information about CMV and basic hygiene measures are straightforward and easily communicated and yet they still remain absent from routine antenatal care in the UK. Sixteen years after my own pregnancy, families continue to report that they were not given any information about CMV and yet they are now living with the consequences. This strongly suggests that previous conclusions have not translated into meaningful change.There may well be updates NICE guidelines for midwives to inform women during pregnancy about the virus, but to do so is not mandatory and it is evident from those with recent experience of any pregnancy that this is not routinely happening and CMV is still not mentioned during antenatal care.

I am also concerned that the review does not sufficiently reflect the benefits of universal newborn screening in enabling early diagnosis, prompt treatment where appropriate, and proactive follow-up for hearing loss and neurodevelopmental needs. These benefits must be weighed not only against short-term costs, but against the long-term personal, educational, social, and economic costs of missed or late diagnoses.

In light of emerging evidence and the continued experiences of affected families, I believe the conclusions and recommendations of the last review should be revisited. A approach that recognises the irreversible harm caused by delayed diagnosis would better support families and improve outcomes. Universal newborn screening, alongside consistent antenatal education, is a must to ensure the devastating consequences of cCMV are reduced.

Discussion comment:

The conclusion does not reflect the scale of harm caused by delayed or missed diagnosis. In focusing heavily on uncertainty and potential drawbacks of screening, the review fails to give enough consideration of the impact the virus has everyday to individuals and their families. Every family affected by CMV will share the view of mine, my son and my family – why had we never heard of CMV ? How can our son be permanently affected by a virus we had never heard of and were powerless to try and prevent. We feel the devastating impact of the virus far outweighs the uncertainties listed as reasons for not moving forward with universal screening. The every day real life emotional toll for the families impacted by CMV and the permanent disabilities and in some cases sadly stillborn or infant/childhood death surely outweighs these uncertainties.

Recommendation comment:

Yes, I absolutely believe universal newborn screening for cCMV should be introduced in the UK.

The benefits clearly outweigh the risks. Universal screening would allow babies with cCMV to be identified early, when antiviral treatment, hearing monitoring and early intervention can make a real difference to outcomes. Without screening, many children are diagnosed too late and often only after irreversible harm has occurred. This means there are lifelong consequences that could have potentially been prevented, or reduced.

From a public health perspective, failing to screen does not avoid harm. Instead it transfers harm onto children and families. Late diagnosis leads to permanent disabilities, increased educational and social care needs, and long-term costs to the NHS and wider society. The human and economic costs are far greater than those associated with screening and early follow-up.

Universal screening would also bring equity. At present, diagnosis depends on chance, parental persistence, or visible symptoms at birth, which many affected babies do not have. A national programme would ensure all children have the same opportunity for early diagnosis and support, regardless of background or postcode.

Given the seriousness of cCMV, the availability of interventions that are time-critical, and the ongoing failure of awareness-only approaches(virtually non existent within the NHS/public domain), universal newborn screening is a proportionate, ethical, and necessary.

Alternatives comment:

Whilst I believe screening needs to be brought in at the earliest opportunity to the UK, there are ways the NHS and government could better support families affected by cCMV and reduce the number of families having to go through such devastating consequences.

Firstly, there must be consistent, routine antenatal education about CMV. Information about CMV, its risks in pregnancy, and simple hygiene measures to reduce transmission should be provided to all pregnant women as part of standard antenatal care. These measures are low-cost and non-invasive, yet awareness remains unacceptably low. Many families continue to report that they were never warned about CMV, demonstrating a clear gap between evidence and practice. This is despite other less prevalent conditions and safety measures being mentioned routinely during such antenatal care appointments.

Secondly, improved training and awareness among healthcare professionals is essential. Midwives, GPs, obstetricians, health visitors, and audiology staff should be equipped to discuss CMV, recognise potential signs, and begin testing and referrals when concerns arise.

Thirdly, the NHS could ensure a more consistent national pathway for testing, such as automatic CMV testing for babies who fail newborn hearing screening or who present with relevant symptoms. At present, access to testing and follow-up varies by region and is often dependent on parental pressure.

Families and parents require better support following diagnosis. This would include audiology monitoring, developmental assessments, and educational and emotional support.

Finally, there should be greater national investment in public health campaigns and research to improve awareness of cCMV.

However, all the above measures should be managed alongside universal newborn screening. Education and awareness alone have not prevented avoidable harm. A coordinated national approach that combines antenatal education, professional training, clear clinical pathways, family support, and screening would offer the greatest protection for children and the best support for families.

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

cCMV has affected and continues to affect my family. Our daughter was diagnosed at around 2 weeks old having failed two newborn hearing tests. She started valganciclovir treatment at approximately three weeks

The first few months of her life were very stressful as we navigated attempting to understand how the virus had affected her. We were however very impressed by the treatment pathway and the care we were given. There were a large amount of appointments and screenings around hearing, eyes, blood tests and an MRI. These were greatly appreciated but were emotionally exhausting and had a significant impact on our mental health, personal finances and the wellbeing of our eldest child.

Our daughter has full neurosensory hearing loss in her left ear and two changes in her brain, we are yet to know the extent that this may affect her development.

Whilst we were very grateful to be able to access treatment for her we do suffer sadness and frustration around why we didnt or couldnt find out about this diagnosis earlier and possibly have had access to treatment antenatally.

The wide range of morbidity relating to this virus appears to make it tricky to ascertain whether to screen for it or not. For those families who have a child affected by it, it is clear cut. More should be done.

Our daughter is wonderful and we are determined that she will live a full and beautiful life regardless of any long term impacts of this virus. In some ways we feel lucky recognising the full and more severe range of complications cCMV can have but in other ways we are sad of the sequence of unfortunate events that led to her being affected by this virus knowing that treatment pre birth may have prevented her unilateral hearing loss and other possible development issues.

We would welcome additional screening for pregnant women who experience flu type symptoms during pregnancy or have other high risk factors relating to CMV

Evidence Comment:

I am not qualified to talk about whether any evidence was missed

Discussion comment:

I wonder whether health economics should also be included within the recommendations or discussions.

The cost of a simple adittional blood or saliva test for pregnant women to screen and a course of valganciclovir must be vastly cheaper than the ongoing treatment and review of children with long term effects due to cCMV and this should therefore be weighted in the discussion around the justification for treating asymptomatic cases or offering treatment without knowing the possible impacts

Recommendations should also consider the upskilling and awareness raising formidwives and peadatricians for clinical signs of cCMV as before failing her newborn hearing test there were signs that our daughter had the virus but these were missed. We will not know what impact if any that two week delay had in terms of her outcomes

Recommendation comment:

Screening should be recommended as the impact of the virus can be so catasprohic and life changing. Whilst there will be risks and balances for clinicians to navigate about when to treat it seems clear that the lead cause of infectious neurological disabilities in children the current offer is not doing enough to fully prevent the wide range of disability and infirmity that could be caused.

I think there should be clear consideration around targeting screening but also universal antibody screening during a first trimester to ascertain whether an issue may be possible

Alternatives comment:

Awareness raising among the healthcare workforce.

Other comments:

I believe I have shared all my views. Thank you

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

Yes, my nephew has the condition and if there was a screening for this he would have been able to have the treatment to hopefully prevent muscle decay and hearing loss.

Recommendation comment:

Yes absolutely screening should be recommended. If families could find out from birth, before 8 weeks old then they will be able to get the treatment as soon as possible.

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

Yes, my nephew was born with CMV but we did not know until he was born. The CMV has given him cerebral palsy and his is mostly deaf.

Recommendation comment:

Yes- it's important to know how babies are impacted and to give their family all the support needed.

Alternatives comment:

Provide more information about CMV- none of my family had heard of it until my nephew was born.

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

Affected my baby.

He has significant development delay

High risk of epilepsy

Potential cerebral palsy

Significant hearing loss

Discussion comment:

Awareness needs to be raised regarding CMV as it's much more common than people would think

Recommendation comment:

It should certainly be recommended as it's a much more common thing than people realise.

Many babies can be born with CMV with no adverse affects, however the impacts can be devastating.

Alternatives comment:

More funding into research regarding CMV to potentially find a cure

---

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

It has affected my gorgeous grandson, if screening was around and offered to my daughter she would have found out in time so when he was born he could have had treatment straight away and not when he was 4 months old and the damage had already it definitely been done

Recommendation comment:

It definitely should be available to every pregnant lady especially the high risk ones that work with children, it would stop babies being born deaf and with muscle

weakness, cmv affects the brain too so it affects the rest of their life's and all the families that are involved

---

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

My granddaughter was diagnosed with cCMV but after antiviral treatment woukd have been effective. Her symptoms at birth were missed.

As a result, she is deaf in one ear and ger parents had to endure months and years of worry about whether long term problems woukd manifest themselves.

Evidence Comment:

As a lay person, the evidence seems comprehensive.

Discussion comment:

Having read the report, I strongly endorse the recommendations that more reseach be done into the feasibility and effectiveness of antenatal screening and treatment of of maternal CMV infection.

There should be targeted screening of babies thay fail their newborn hearing test.

Trials of valaiclovir should be conducted as soon as possible.

There should be an information and education campaign to raise awareness of cCMV amongst parents.

Recommendation comment:

Yes..see above. If there had been antenatal and postnatal screening, my granddaughter wpuld not be suffering her hearing loss..and potentially, worse impacts.

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

My son has been living with the impact of the virus for over 20 years. He is profoundly deaf, has a language disorder, vestibular issues and epilepsy. He finds communication difficult. He does not have many qualifications and is finding it hard to get a job. The virus has impacted our family in many ways. The focus has been very much on our younger son with many appointments and tests over the years. Due to the number and frequency of appointments, I left my job when he was young and now work part time locally. We find our life as parents fits around him whether it is transporting him, helping his day to day living or taking him to disability groups. He needs support with many things. We have learnt sign language to help him. He has many strengths and a great sense of humour but there is no doubt that the virus has had a huge impact on his life and potential life, and ours as a result. It is impossible to describe the emotional and personal costs to us as a family.

Evidence Comment:

It would have been important to have heard more about the family experience, particularly where their baby was not tested at birth. The family experience is not really included in the report which makes me feel sad that this opportunity was missed. The impact on families does not come through particularly in relation to what happens if a baby is not diagnosed at birth and the family have to wait for the heel prick test. For example we had to wait three years for CMV to be diagnosed which meant that we were worried and concerned. Our son had invasive testing (under anaesthetic) because they thought he had something progressive. No one thought of this common virus until our neurologist took his scans to a conference abroad. These individual stories make the difference. It does not make it clear how important timely diagnosis is and how long the heel prick test takes to come back. If would have been important to work out the costs to families and society of an individual child and compare that with testing every child.

Discussion comment:

As I mentioned above, family experience is an important omission. If someone was reading the report that did not know about the virus, it may appear that it was not serious. To many children it is and totally impacts their lives. The conclusion and recommendation are disappointing. If there is a reliable simple test and testing in other countries, we should test here. Other countries have decided there is enough evidence so why is it not enough here. If would have been important to work out the costs to families and society of an individual child and compare that with testing every child. As far as I can see there is no mention of comparitive costs.

Recommendation comment:

Screening should be recommended. Our son’s story is not a sad anomaly from years ago. He was seen by three different paediatricians none of whom mentioned the virus. It is shocking that this situation might happen again. It is very rare now to talk to anyone in the medical profession that knows about the virus and if I tell anyone

else what caused my son's deafness they have never heard about the virus. Everyone should know about the virus and the affect it can have on the unborn baby especially if they pregnant and have toddlers at home or work in child care. Because there is so little awareness and many babies don't have symptoms, the only way to help other babies is to test. Every time I fill in this consultation I cannot help but think of the missed opportunities to diagnose my son and how many appointments and anaesthetics could have been avoided. He had symptoms on his brain in the scans and when he was born was weak on one side and had a classic rash. from about 18 months, we felt that he couldn't hear but no one listened to us. Had they tested for CMV they could have monitored his hearing and he would have been helped earlier. It is hard having your concerns as a parent dismissed. Now I know there is treatment too so diagnosis is even more important.

I also note that there are some other countries that are screening and that some areas of the UK have targeted screening. I find it hard to accept that whether your baby has a simple test that might improve their life chances is dependant on where you reside and what hospital you go to. We need to make it fair across the UK

Alternatives comment:

As I suggested above, we need greater awareness in the medical profession particularly midwives who see pregnant women. We also need greater awareness in the population generally so they know what to look for.

I note the report discusses targeted screening after the hearing test, this would be a start. The report says it would miss some babies but it must be better than not testing any baby. If you introduced this type of testing, perhaps other people in the medical profession would hear about the virus and know it was something to look out for.

Other comments:

I recommend that in future reports you include the family comments, make the plain english summary more detailed. families do not have time to read everything but the summary does not have enough to comment fully. I recommend this is looked at again very soon. We should not lose momentum and fall behind other countries. Every child that is not tested and has difficulties is important

---

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

My daughter was born deaf in one ear as a result of cmv.

Evidence Comment:

Earlier testing and capture may have led to some of her hearing being retained.

Discussion comment:

No

Recommendation comment:

Yes it should be recommended to try and manage the virus should it be present

Alternatives comment:

Screening!

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

My granddaughter has serious hearing issues with an uncertain future whether her hearing continues to deteriorate and possibly have some other health issues developing.

Evidence Comment:

The impact of this virus can be profound and the recommended approach appears dismissive and paying lip service to future action. Public knowledge is very limited and the approach is inadequate.

Discussion comment:

There is insufficient weight given to the seriousness and impact on children and their families. It appears that the ‘buck’ is being passed to families, local health services and education. These are poorly resourced and surely developing prevention and early intervention which screening enables is so much better than the inadequate recommendations. Screening is an enabler to improvements through the system.

Recommendation comment:

Screening should be recommended to promote education, early identification and promote research on best ways to develop prevention or treatment options in future. Screening is also a valuable data source to direct resources towards public health approaches, prevention and future symptom management. The current approach

abandons children and parents and leads to the NHS and Society bearing significant costs financially and emotionally.

Alternatives comment:

There is no real alternative apart from early identification. Local NHS services are poor in identifying the problem and initiating care plans. There are too few clinical experts and they get involved too late in the development of the clinical issues.

Other comments:

Screening, Research and Education – they go together in a joined up and effective system.

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

Yes, CMV has greatly affected my daughter, myself as her mother and my family. From asking other family members for extra help with childcare to extra costs of multiple hospital trips, often travelling to specialists over 200 miles away. My daughter was born with symptoms of cCMV, she had petechial spots and unilateral hearing loss which further deteriorated to bilateral profound loss at the age of 3. The chance of this deterioration could have been reduced by up to 50% if she had had anti-viral treatment from birth. She is now 5, wears cochlear implants and attends a school with a special provision. She uses BSL to communicate and attends speech therapy once a week at school. She also has a vestibular balance loss linked to CMV which affects her ability to walk and balance herself. We attend a vestibular balance physiotherapist at XXXX XXXX for her.

Evidence Comment:

My daughter displayed symptoms of the virus at birth but was dismissed due to Covid. She failed her Newborn Hearing Screening, had a head circumference on the 4th percentile and had petechial spots. Covid caused outpatient closures causing her retest to be performed at 10 weeks old, with a referral back to the hospital at 11 weeks for further tests and finally a diagnosis at 12 weeks. Under current treatment guidelines for the virus, she had missed the treatment window. Having spoken to further professionals afterward many of the staff on the ward she was birthed did not have any prior knowledge of the virus as its an optional module with the NMC.

Prior to all of this during my 5-6th month of pregnancy with her I myself displayed symptoms of an absolutely horrendous cold passed on from my eldest son. It took

almost a month to go away and i attended my GP surgery at the time who said “there is no magic pill when you are pregnant” didn’t even physically examine me (didn’t take my temp, look in my ears, listen to my chest or anything). Now I know this was the virus.

After it was identified in my daughter’s urine sample at 11 weeks her newborn blood spot was checked and this returned negative. It came with a warning of false negatuve results and my pregnancy screening bloods were checked and i had a more recent blood test checked from after birth. These showed my blood had serum converted during pregnancy from cmv negative to cmv positive.

Discussion comment:

It sounds positive that the recommendation is in favour of a more in depth review.

Recommendation comment:

I think it should because our family has been greatly affected due to the lack of screening and identification either prior to birth or at birth.

Alternatives comment:

My only comment on this would be that all hospitals with birthing units should have a percentage of staff trained in identifying possible cCMV symptoms at birth and furthermore there should be a minimum percentage of those trained on each shift. A lot of the issues we have faced not just in the antenatal period but up until now could have all been reduced if it had been identified during pregnancy or even at birth so correct treatment could have commenced at the right time.

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

My grandson was affected by CMV and nobody knew about it even the nursery where my daughter worked,so I think there should be more awareness of this condition especially in nursery’s and pre schools.

Evidence Comment:

More action should be done to prevent cmv in pregnant women working in nursery’s

Discussion comment:

More education in sectors working with young children to prevent pregnant women contacting cmv

Recommendation comment:

Definitely, screening should be recommended

Other comments:

Pregnant women not to change nappies when working with babies and young children

---

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

Affected my son

Recommendation comment:

The screening should definitely be a thing!

CMV isn't always visable, some babies have been born and show absolutely no sign that CMV has affected them.

Treatment is recommended for babies before 8 weeks to stop further damage to hearing & muscle weakness and without the screening many many babies miss this period which unfortunately my son did too.

The only reason we knew my son had CMV is because he had unexplained hearing loss and they tested into why this was and this is when CMV came around. Without this we would have absolutely no idea and he would've completely gone untreated for way too long.

CMV screening will save a lot of futures babies development allowing them to have early treatment

And intervention

Alternatives comment:

Spend more money into research

Increase awareness of CMV

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

My daughter was diagnosed with cCMV in XXXX XXXX and a result of this has unilateral deafness in her left ear. She started off with moderate deafness but it has since deteriorated and she is now left deaf in that ear.

Her MRI showed inflammation in the white matter in her brain which will most definitely cause issues in the future but we are fortunate that currently this has remained dormant.

It has been a very stressful time going to and fro with appointments and constant worries of how the virus will affect my daughter. On top of this, the anti viral treatment is likely to have severe affects to her immune system and cause a range of future problems.

Evidence Comment:

Because of a lack of understanding of the severity of the virus; a slow audiology booking system and (most importantly) botched swabs, my daughter was diagnosed late and treatment started far too late which at believe contributed to the deterioration of her hearing.

Discussion comment:

I wish to request that cCMV is included in early screening to ensure that infants can have treatment as early as possible in order to prevent the deterioration of deafness and other disabilities that the virus causes.

Recommendation comment:

Screening is recommended to ensure that infants can have treatment as early as possible in order to prevent the deterioration of deafness and other disabilities that the virus causes.

Alternatives comment:

Educate more professionals in the NHS: midwives, GPs, nurses.

Educate environments where the virus spreads and urge better risk assessments for staff: nurseries, schools, care industries.

CMV is caught more easily than listeria and toxoplasmosis, yet no midwives or antenatal teaching mention it.

Other comments:

Raise more awareness of the virus.

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

My niece 4 yrs old is deaf from one ear and 80% deaf on the other one. And hearing seem to be decreasing so could become fully deaf

Evidence Comment:

Allow screening to detect and support earlier

Discussion comment:

Please allow screening so children cam be fully supported from birth

Recommendation comment:

Yes. This would have helped putting more support in place and prepare the family

---

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

I think I was in my early 20's when I first caught cmv I believe from a friend, I don't remember if I was ill at the time but my body coped well. I fell pregnant when I was 24 years old. Pregnancy was o.k, I developed colistasis during and my baby was monitored weekly. I hemorrhaged as I was giving birth but didn't require a transfusion. My daughter was jaundice but didn't require treatment, she was beautiful, healthy, perfect. Unknown to me we had cmv then, but I believe at a low viral load. I caught the virus again again from our mutual friend but this time a massive viral load. My daughter and myself became extremely poorly, I didn't

understand what was happening to us, everything was malfunctioning with our bodies, physically, emotionally, mentally. I'd wake in the morning and think whats gonna going to go wrong with our bodies today and was in sheer panic at the health of my daughter, roughly this went on over a period of possibly a year ish and we deteriorated as it went on. A living hell, dealing with doctors was difficult although I liked my G.P no matter who I saw they didn't understand? Believe? the situation and thought I had health anxiety, I felt so alone, none of my family believed the situation either. It was me dealing with doctors, I would of giving up if it wasn't for finding out what was happening to my child. So much was going wrong physically, my daughter looked like different child, the colour of her face was strange, seemed transparent in a sense, pale, she was darker around mouth, telangetasia on skin, eyes had broken broken viens, I'd say her face changed even the she looked, she'd cry saying she didn't know why, scarlet fever twice constant illness, this is scratching the surface of what we when though, trouble breathing which was never explained, I developed ataxia, so, so many symptoms from not being able to feel myself wee, to hair falling out, my six year old developed grey hairs! I didn't feel life was real. In the end it was found I'd developed celiac through a blood test measuring 200,my daughter was in 160's though it took a while to get her tested because I wasn't being taken seriously. During this time I noticed many others getting ill in different ways from strokes to cancers, pneumonia, children being born with genetic issues that weren't previously in the family. I didn't know what infection I'd caught at the time, I researched. We became a lot better on the gluten free diet. I had a daughter 4 years later, during the pregnancy a neighbour had a son he was born deaf, it was cmv. I knew what the infection was, my daughter was born on time, she had seizures, I filmed them, doctor agreed but eeg didn't confirm, she's lovely but challenging, I think possible adhd and maybe autism. More words needed.

Evidence Comment:

I'm sorry but I didn't read very much, please still consider my opinions, views, possible suggestions. What I did read was fine but I think more research needs to be done on the outcomes of cmv, the co-infections that seem to come with it, i.e strep a, staph, E. coli others. Also it's possible mix with other viruses. From what I've read I really don't think the consequences of cmv are being fully understood, compared to the experiences of my family's, friends and people that have been around me. I think this needs to be a major priority, otherwise in years to come I believe there's going to be significant issues arising with how other infections associated with cmv or because cmv is having a significant impact on the immue system function causing problems for people, autoimmune, cancers, genetic based. I believe I caught the infection in XXXX XXXX.

Discussion comment:

I didn't read this.

Recommendation comment:

I do, I know that with my second daughter, we needed to find out. Treatment may have helped with her seizures although they did stop, and it may have helped with development, she may not of had such extreme reactions to the suggestion of eating something she doesn't like, her diet is minimal, or even just getting her to eat food from Marks and Spencers which she won't do. And so that she had more of a chance than just being left. I'm lucky because she has developed though, she's lovely and funny, she communicates, but I believe cmv has done damage to her and she's a different child to one she would have been without cmv and will struggle more. It's also an explanation for us parents to why our child children are struggling, maybe some don't want to know but I do. We can see sign and help early on. Cmv is a catastrophic infection that needs to be better understood. I think that if as an adult we develop flu like symptoms cmv should be tested for as it has subsequent effects on adults too. I believe if the burden of this virus was really know, it would be uncomprehendable to people and nhs and if a solution was found life would be so different for many, especially babies born with this life destructive virus and this is why you've got to start doing something about it now. Please, please don't wait anymore years on the decisions to test new born babies for the virus and viral load if detected. I do understand however better testing still needs to be developed and anti viral-treatment for people that have it already and vaccine. I know in one sentence I wrote something that so hard to do but it must be done somehow. More money needs to be provided.

Alternatives comment:

Teach kids in school more about keeping clean, hand washing before food, etc. Teach them bit about infections and disease, virus's that are out there, of course in the correct way for there age and again if they go to university, I don't know if this done already. Also teach them all the ways it can spead.

I think the advice given to pregnant about not sharing cultury etc. is ridiculous, that's unrealistic for 9 months and it will be spread in other ways, as it's viralance is beyond any other infection I know off in this present time.

The test could be offered as a choice for parents, it would help your organisation understand it more, benefical for future children. Children with cmv monitored over the years

More money provided for the development of vaccines, tests, antivirals, treatments. This is nesseccary. I do need to put I haven't tested positive but I believe I have it, I believe we developed the antibodies to celiac instead of cmv.

Other comments:

Public need to know more, this is how we progress, we don't know who may find a vaccine or treatment but the more people who know the more chance of it happening in the future. It is an terrifying virus but the quietness that seems to be around it i don't think helps.

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

My daughter was diagnosed with congenital CMV at 2 weeks 6 days old after failing her newborn hearing screening.

Because she was swabbed for the virus routinely due to failing multiple hearing tests we were able to get her diagnosis quickly. This also meant we were able to access treatment which was promptly started prior to the 4 week cut off point.

My daughter has a unilateral hearing loss which is irreversible. She also has damage to her brain which requires regular development reviews to see what delays she may have.

We also have to regularly have her hearing and eyesight checked.

She is only 9 months old and we have spent so much time in hospitals. She has endured so many tests, blood draws and a 6 month treatment programme.

All of this for a virus we had never even heard of. Why was I not made aware of this virus at any point in my pregnancy or previous pregnancies?

Why is it that in our friends and families no one had heard of this virus or the severe damage it can do? Why is there so little information about cCMV?

Our daughter has life long changes from a virus that she caught while in utero.

If I had known I had not had this virus before and that catching while pregnant could have life changing consequences for my baby I would have been able to make changes to better protect us.

My baby and I were not given the chance.

When I was poorly with a flu like illness at approximately 25 weeks I ended up seeing the GP, I was so unwell and there was nothing they could prescribe other than a nose saline. At this point why did no one even mention CMV to me? If treatment for my baby girl had started at that point, she could have been born with no brain damage, she could have been born with full hearing.

This virus stole so much from her and we have to live with the worry that it could still in the future render her completely deaf or blind or with further deficits.

Every pregnant woman deserves the chance to safeguard their baby from something this impactful.

We know not to eat certain cheese in pregnancy, but no one warns you about this?

Recommendation comment:

I think some form of screening should be recommended.

If in a women's booking in bloods they could know if they have had CMV before it can help support women and their midwife care team if any precautions need to be made in their pregnancy.

Other comments:

Awareness needs to be increased. All women should be told about CMV in pregnancy.

GPs should know about the virus.

When we were given our daughters diagnosis we had so many questions for our consultant. One of them was whether this was a risk to other people or not. She ensured us that our baby posed no risk to children and adults but we needed to be careful of immunosuppressed adults and pregnant women especially in first trimester. Also that it was only passed on through direct liquid contact so saliva or changing a nappy. Because you don't know who is in early pregnancy or not we generally made friends who could be pregnant aware. One person (who wasn't pregnant) spoke to her GP who gave her bad advice and this person along with her entire family avoided all contact with not only my daughter but also myself, husband and our older child.

Had this GP had up to date advice they could have reassured this person, instead an avoidable saga came about because of a lack of understanding and training on cCMV.

I still can't believe, even in medical fields, how much of a lack of understanding and awareness there is. This has to change. Our children deserve better.

Because we knew when her viral load was so high to avoid close contact with specific groups, we could do our best to safeguard and protect those around us.

Nobody gave me that same grace, I was not afforded the same privilege. And my baby paid that price.

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

My son was born with cCMV in XXXX XXXX. At the 36 week scan his growth rate in the womb had dropped significantly, mum was monitored and the drop in rate was put down to a possible miscalculation at an earlier scan. Waters broke at 37 weeks, labour never started, emergency C-section, and born 5lbs, “diddy” they called it. He had jaundice. He failed two newborn hearing screenings, and we were told it’s most likely mucous. He and mum were kept in 6 days post-birth, and checked on – but no one seemed to know if anything was wrong with him and we were sent on our way.

At no point in this time was CMV checked for or even mentioned. At 4 weeks old he had a follow up audiology appointment and was found to be bilaterally profoundly deaf, the audiologist asked if she could swab for a virus known to cause hearing loss. This was the first time it was ever mentioned. Antivirals (Valganciclovir) are meant to begin within the first 28 days of life with a positive cCMV diagnosis, he was only able start them at 6 weeks old, as he was only swabbed at 28 days. Too late! The swab should happen within 21 days to better accuracy, mum’s bloods had to be re-checked to confirm.

If you look at the whole picture; drop in foetal growth rate, labour unable to start and causing stress on the baby, low birth weight, jaundice, failing two newborn hearing screenings and CMV not even being mentioned or swabbed for? Even failing a single newborn hearing screening should trigger the need for a swab. No Doctor, midwife, NCT class, health visitor ever mentioned CMV. It’s the biggest cause of childhood non-hereditary deafness, yet when your baby fails a newborn hearing screening they ask if you have any deafness in the family and then don’t swab for CMV?!? Audiologists seem to be aware of it but very few other medical professionals do. My son also had an MRI and some abnormalities were found on his white matter. He now has two cochlear implants, he had the surgery for this at 8 months old. But all the NHS website can say is “sometimes it causes problems” or like the evidence pack “200 babies a year will develop long term problems” – like those 200 babies and their families don’t matter because screening seems too much of an effort. CMV is a cruel, indiscriminate, destructive, and devastating virus that with screening and education can be greatly reduced.

Recommendation comment:

Yes screening should be recommend. I think that it’s a fundamental misinterpretation of data to think that because at screening you can’t tell which babies will go onto develop long-term issues that there then isn’t an issue, or you don’t know whether to treat them or not. They could be monitored and flagged in the system to keep an eye on their development. Many children go on to develop things later in childhood like hearing-loss or cerebral-palsy, or autism, or other learning difficulties – which seemingly have ‘no cause’, but may well be attributed to CMV, we will never know.

If routine screening is done it will also drastically increase awareness amongst the general public and medical professionals. Thus when a baby is diagnosed with cCMV it isn't an out of the blue shock to the family and they can be better equipped to deal with it, without having to explain repeatedly to medical professionals what it is. With greater education pregnant mums with young children will be more careful with handwashing, sharing food, and nappy changing, as well as pregnant workers in early years care will be more careful too, this will in all likelihood reduce the cases of cCMV.

Screening leads to greater general awareness, which leads to an overall reduction in cases, which in the end costs less money. What's not taken into consideration is the lifetime costs of the issues CMV causes, my son is one case but 2x Cochlear implants (£60k-£100k), Audiologists, Speech and language therapists, Teachers of the deaf, 6 months of Anti-virals, countless medical appointments in 3.5 years of life. There are children who can't walk, who can't swallow, who can't talk, children with learning difficulties, children with vision impairment, organ issues. How many millions is that costing over a lifetime?

One of the arguments against screening is "we don't want to put more undue stress on expectant mums / parents". You already get tested for far less likely things in pregnancy and at birth, when you say yes to all those screenings and checks, and everything comes back negative in pregnancy and post-birth and you think you might be in the clear, I can tell you that nothing is more stressful than receiving a diagnosis for something you didn't know existed, yet is quite common and you have no idea what damage it may cause your child.

Diagnosis is the worst part of any CMV journey, and I would not wish that upon any parent, let alone the children who have to live with the effects of it. A screening to see if you have CMV or not, and turns out not? The stress of that? Nothing. It turns out you have it? Oh okay now we know – what do we do? How do we proceed? Arm us with the facts. I would give anything to have had diagnosis journey like that and not feel like the first year of having a newborn was stolen from me.

Alternatives comment:

Education. Awareness. Education. Awareness. Education. Awareness.

First and foremost this needs to be acknowledged as something that exists and causes a multitude of issues in thousands of families. It feels as if the families dealing with it and the handful of infectious diseases doctors, and audiologists are the only people that know about it.

If people know about it they can deal it, they can potentially prevent it if they already have children and are having subsequent children.

Although like my son I think there are many of cases where it's the first child that's born with cCMV, I've met plenty of them. They're not just a number on some data set of 200 babies a year that might have long term problems.

Other comments:

If universal screening isn't an option, what about screening / swabbing any baby that fails a single newborn hearing screening. That would be a start, more screening and education can expand from there.

Name: XXXX XXXX

Email: XXXX XXXX

Condition: Cytomegalovirus

Affected Comment:

It has affected my son who is now nearly ten months old. As a result of congenital CMV he has severe hearing loss in his left ear and partial hearing loss in his right. He also has some cystic changes on his MRI brain scan, although it is uncertain how this will affect him as he gets older

Recommendation comment:

I think it should be recommended. I was poorly with meningitis at the time of my son's birth (which was unrelated to the CMV) and because of this he had his bloods done which showed low platelets caused by CMV and allowed an early diagnosis. Other than that he did not have any signs of CMV at birth and therefore would not have been tested otherwise until he failed his newborn screening, by which point he would have missed the window for starting antivirals within the recommended 28 days to hopefully prevent further deterioration in his hearing. Screening would have detected this and ensured he still got the antivirals early.

Alternatives comment:

There needs to be a huge awareness campaign for this condition. I worked in healthcare and was completely unaware of the risk of congenital CMV and what this was. I think most people are aware of toxoplasmosis and listeriosis as risks to an unborn child but I know almost no one (including many doctors and midwives) who are aware of the condition and it was not present in my handheld maternity notes. Yet it is far more common. I feel angry that I wasn't aware about this and guilty that I could have done more to prevent this damage to my baby.

Name: Chrissie Jones
Email: XXXX XXXX
Organisation: XXXX XXXX
Role: Professor of Paediatric Infection and Immunity

Publish submitter's name: True
Publish Organisation name: False

Condition: Cytomegalovirus

There is now increasing evidence from the US and Canada on screening of neonates and I urge the committee to carefully reassess the evidence, based on this new data. It has been shown to be feasible to do so on a large scale. There is also new data since the last consultation of hearing outcomes of infants treated with valganclovir and better outcomes for these infants. Without screening, infants who are eligible for treatment are missed with life-long harms.
France has very recently introduced screening in pregnancy as a national recommendation. This is based on the evidence of a significant reduction of transmission of infection to the foetus when primary infection is identified early. Without screening this is impossible.
Moderna has recently discontinued its programme to develop a CMV vaccine for the indication of congenital infection. Therefore there is no vaccine now in later stages of clinical trials and therefore it is likely to be many years before a vaccine is available now. Risk reduction is the only strategy. There is evidence that knowledge of CMV serostatus allows women to assess their risk and make informed decisions about adopting risk reduction measures. Screening is needed to inform this.
I urge the committee to carefully assess this new evidence for maternal and neonatal screening to reduce the life long harms to infants.

Name: XXXX XXXX
Email: XXXX XXXX
Organisation: XXXX XXXX
Role:
Publish submitter's name: False
Publish Organisation name: False

Condition: Cytomegalovirus

Until there is more research based evidence available on the positivie test rate for cCMV screening may not be useful at this current time.

Name: XXXX XXXX
Email: XXXX XXXX
Organisation: XXXX XXXX
Role: Consultant Virologist
Publish submitter's name: False
Publish Organisation name: False

Condition: Cytomegalovirus

Antenatal screening: I agree that a formal expanded evidence review is required. The limited evidence review does conclude that further valaciclovir vs placebo RCTs would be required, but I think this fails to consider that ethical implications likely make this impossible as the clinical equipoise between intervention and placebo has been lost on the basis of the initial trial results. This must especially take into account the area of medicine (pregnancy) involved and the implications for conducting ethical research. The compound issue in this setting is that diagnosing primary CMV infection within a timeframe to offer effective treatment to reduce foetal transmission is practically impossible within current testing strategies.

Neonatal CMV screening: Agree with findings here. We also have currently unpublished evidence through using a respiratory panel on newborns that also includes a suppressed CMV target. We have picked up zero incidental congenital CMV infections, but have come across false positives, either from contamination within the PCR run or, possibly, from reactivation in breast milk given prior to swab collection.

Name: CMV Action Charity
Email: XXXX XXXX
Organisation: CMV Action
Role:
Publish submitter's name: True
Publish Organisation name: True

Condition: Cytomegalovirus

CMV Action can provide a unique perspective based on the experience of those we support.

CMV Action has been supporting pregnant women and families with a child diagnosed with congenital cytomegalovirus (cCMV) for over thirteen years. Those currently answering the support requests have been with the charity for most of that period and have heard the devasting impact the virus has and the cost to families. In terms of babies and children, we regularly hear about the lack of awareness amongst the medical profession and the impact of delayed diagnosis. There is a lack of information about the true burden of disease and number of cases due to lack of consistent testing which is hampering awareness and understanding of the virus. We also have had trustees with personal experience who are motivated to change the experience they have had themselves.

In addition to individual support, we also hear about the experiences of families who are part of our wider community. We have a private Facebook group with 605 members and recently started a WhatsApp community and family panel after a grant from the National Lottery for a project we named "CMV Connect".

We are the only UK based charity giving support to those affected by the virus and are supported by a team of medical advisers. We are regularly invited to take part in research and attend conferences to give the patient viewpoint. For these reasons, we feel able to offer an informed perspective on how lack of screening impacts on babies and families and why it is time to implement it. Our trustees and support volunteers are concerned that there has been little change in the patient experience in over thirteen years despite more research and treatment opportunities. The charity has heard the accounts of lack of awareness, late diagnosis and missed opportunities for treatment for years.

EVIDENCE MAP OF ANTENATAL SCREENING
As a charity that supports pregnant women we are aware of the difficulties the virus can cause the unborn baby and the impact this has on families. Parents tell us that midwives and doctors have limited awareness of the virus with some being told it is a rare condition. We support the report's recommendation for a systematic review.

We would like to comment that the discussion of the condition gives a figure of 202-216 babies experiencing long term difficulties (page 8). We discuss below why we feel this is an underestimate. However, we would also emphasise that the report does not include important information about the impact the virus can have on the unborn baby where the pregnancy does not continue. We support families where the virus has resulted in pregnancy or baby loss. Any subsequent reports should reflect this when describing the condition and include the experience of pregnant women and their families.

We would ask that the systematic review is completed as soon as possible. Other European countries are moving ahead in this area with the French National Authority for Health recommending systematic screening in pregnancy for those who are seronegative or of unknown status. Their reasoning for the decision is the burden of CMV, inequalities in screening and the existence of a test and treatment. All these factors are relevant in the UK and there seems no reason to delay.

SYSTEMATIC REVIEW OF NEWBORN SCREENING: Our comments on the specific matters in the report.

We recognise the meticulous research and preparation involved in the external review (systematic review of newborn screening). We were pleased to have been able to attend some of meetings with the team involved but feel that our concerns are not fully represented in the report. Our medical advisors are submitting responses that comment specifically on research findings and conclusions, but we would like to stress the following points based on our experience of working with affected families:

Plain English summary: Insufficient discussion on unique timelines.
The summary is where many responding to the consultation will find the information on which to base their responses. The individual consultation

responses form (Question 1) invites families and friends who know the impact of CMV to respond. Given the complexity of CMV biology, diagnosis and treatment, not all people responding will have comprehensive knowledge about cCMV and many parents will rely on the summary rather than read the full report.

The plain English summary does not draw out all the salient points, particularly the essential timelines for diagnosis and treatment, which will make it difficult for individuals to give informed responses. At line 9, the summary states that newborn testing is being considered up to 28 days. It is not apparent that diagnosis must be within 21 days to confirm that the virus was contracted in pregnancy rather than acquired after birth. Also, it does not mention that treatment should be started in the first 28 days. The recent ECCI guidelines (Lancet 2024) reports studies showing benefits where treatment starts in the first month. They conclude that it is uncertain whether starting later reduces the efficacy of treatment. This is highly relevant information as we understand these timelines for diagnosis and treatment are unique to cCMV. It would have been appropriate to include this so those responding to the consultation were fully informed.

Comments on the body of report
We think it is important to highlight where points raised do not fully take into account the practical realities and impacts on families, and points where the report could have had more clarity.

(i) number of babies
The report states that 200 (page 8, line 16) or 202-216 (page 13) babies a year experience long term sequelae either at birth or later. The recent Lancet report indicates that the risk of long-term impact is 17-20%. Whilst it is difficult to accurately assess this in the UK due to lack of consistent screening, the report's conclusion on the numbers seems conservative. A 2022 review (Jones et al., Arch Dis Child) used a retrospective cohort study from the Netherlands to estimate the number of infants affected by long-term adverse outcomes in the UK as 931 per year, which our medical advisors refer to as a best estimate. Relying on a potential underestimation may lead to under-recognition of the burden of disease and impact on the case for screening.

(ii) predicting long term problems
On looking at potential adverse outcomes the report looks at several studies. MRI and ultrasound are identified as promising in terms of ability to predict long term difficulties such as epilepsy (page 52, p70). However, the report states that the most reliable way of predicting adverse outcomes is still symptoms at birth or timing of maternal infection (page 70). In terms of symptoms at birth, we regularly hear cases where lack of awareness has meant that even obvious symptoms at birth do not automatically lead to a test for the virus. We recently reviewed cCMV testing guidelines and protocols across several NHS trusts and found enormous variation in the types of symptoms that are recommended to initiate a CMV test (and indeed, whether trusts had cCMV guidelines in the first place). In terms of the MRI, if a baby is asymptomatic and not tested, it will not have an MRI so any

neurological issues will not be identified. A 2020 study testing all babies born in one hospital (Blazquez-Garmero et al Pediatr.Infect.Dis.J 2020) found that half the babies found to have the virus had abnormalities on cerebral imaging which would not have been identified without testing. In relation to timing of infection in pregnancy, the majority of pregnant women and babies are not tested in pregnancy so those looking after them will not be aware of the timing of infection. Therefore, other than symptoms in the baby, the two potential ways to predict long term outcomes will not be considered unless a baby is tested.

(iii)arguments against universal screening include the fact that most babies tested will not go on to develop long term sequelae caused by CMV (page 90). However, these babies would be monitored to check this in contrast to the situation now where concerns are dismissed. One argument given against targeted screening after the newborn hearing screen is that this screening would miss asymptomatic cases or those without hearing loss (page 91). These two conclusions are contradictory. Universal screening is rejected on the basis that it would identify those with no symptoms in the future, and targeted screening is said to miss those that have certain symptoms. The report fails to consider these two approaches alongside one another, leading to a conclusion that risks failing the significant number of children that will experience long-term and life changing symptoms.

(iii) testing after newborn hearing screen
We do not feel that the way the report looks at this adequately addresses the complexities involved. This is a significant omission.
The report concludes (at P91) that it remains to be shown that targeted screening and subsequent antiviral therapy leads to better clinical outcomes than ad-hoc testing for cCMV or treating symptoms as they emerge. Ad hoc testing and treating symptoms as they emerge is totally unacceptable to parents and clinically inappropriate. It also misses the key point that there are tests that can confirm the virus within the window where there is evidence for antiviral treatment. It is precisely because testing is done after symptoms emerge rather than proactively that babies currently miss out. Due to a lack of consistent screening, the number of cases where children are missing out on treatment that could effectively treat their symptoms is likely to be significantly underreported and not recognised in the report.

The views of the charity on behalf of those we support.
(i)Impact of not having universal screening
A constant concern raised by parents during support or when sharing their experiences is the impact of their baby being tested late. Parents generally feel let down by the medical profession and often tell us that if their baby had been tested at birth many of the difficulties they faced could have been mitigated. The timing of diagnosis of cCMV is critical. If it is not within the first 21 days, parents have the wait to obtain the blood spot test result. This means that they often miss the optimum window for antivirals. It is also important to remember that diagnosis is not just about antivirals but is also important to initiate effective monitoring, particularly for hearing. Many parents we support indicate that they shared

concerns about hearing and development which were dismissed. A confirmed result for the virus would have meant that their baby was monitored and any concerns were not dismissed.

In 2025, CMV Action were included in research looking at the consultation responses from the NSC consultation in 2022. These responses echo the position of the charity that failing to test all babies causes issues around appropriate treatment and an impact on the parents. The article identified two overarching themes within the consultation responses: missed opportunities for treatment and the emotional impact attributed to lack of screening. In addition to individual responses, we urge the NSC to consider the analysis of the previous responses which were published after the report was written. (Greiner et al. The Impact of, congenital cytomegalovirus among families and caregivers: A qualitative analysis of response to the public consultation on newborn screening in the UK). The researchers comment on the often lengthy and distressing process of diagnosis. Opportunities were missed for a timely diagnosis which in turn resulted in missed opportunities for intervention and support and emotional consequences. A CMV diagnosis is described as a "gateway" to appropriate monitoring, particularly of hearing. Respondents' beliefs that opportunities had been missed to avert more serious symptoms or impairment led to an "enduring sense of injustice, unfairness and having been let down by the healthcare system" and also missed opportunities for emotional support.

(ii) Inconsistencies in testing for babies not passing the hearing screen
The position for parents who have a baby who does not pass the newborn hearing screen is equally difficult. The NBHS is not aligned with the guidelines for the confirmation of cCMV and treatment. Parents tell us that they did not realise the importance of attending the test with audiology promptly. These pathways need to be aligned and appropriately measured so that all babies attend audiology before 21 days and that there is targeted screening after the newborn test.

The postcode lottery and consequent inequality in outcomes is something that parents feel very concerned about. As the report states, we are aware that some trusts are using targeted screening approaches. Between August 2023 and February 2024, we attempted to establish what the current national position was by collecting FOI requests to confirm which trusts had targeted screening pathways. We sampled the results from 32 trusts who answered our request and had paediatric audiology departments and found that only 7 tested babies either before or at referral to audiology. The conclusion from this was that the majority did not test until confirmation of hearing loss and therefore due to the NBHP this could be up to 28 days after the newborn screen. The timing of testing for a baby who does not pass the newborn hearing screen, and subsequent opportunity for effective treatment, depends on where they are born. The presence of targeted screening pathways being pioneered by a small number of trusts indicates the procedural and economic feasibility of this approach but also highlights inequity in diagnostic and treatment pathways across the country.

The only way to demonstrate a commitment to every baby is for them all to have the same opportunity. Babies who appear well at birth but do not pass the hearing screen are likely to miss the window for treatment if testing is delayed. A recent retrospective review found that 10% of neonates who were otherwise well at the hearing screen were subsequently diagnosed sensorineural hearing loss were identified as having cCMV. The review says this highlights the pathway's diagnostic utility (see Hagan et al European Journal of Pediatrics 2025).

In addition, screening is highly acceptable to the population. For example, we were involved in a research project that involved screening pregnant women for the virus. Out of 3975 women who were offered screening only 3% (144) declined. (Calvert et al Changing knowledge, attitudes and behaviours towards cytomegalovirus in pregnancy through film-based antenatal education: a feasibility randomised controlled trial of a digital educational intervention BMC Pregnancy and Childbirth 21(1),565).

(iii) lack of alternatives to screening
The alternatives are limited. Moderna has recently discontinued its programme to develop a CMV vaccine and so antenatal risk reduction is key. Our experience of talking to pregnant women and midwives, is that there remains a lack of awareness on these risk reduction recommendations. Despite CMV being included in the NICE guidelines very few midwives seem aware of this, and parents tell us they were not told about the risks. Screening is what families want and they do not understand why it is not available.

If every newborn baby cannot be screened, there should be CMV testing for every baby who does not pass the newborn hearing test. This is because the NHSP programme standards (NHSP-S04 referral time from screening outcome to first offered appointment for assessment/ NHSP SO5 attendance) are not aligned with the unique timelines for the virus. Part of the attractiveness of this option as an interim step, is that it may increase awareness and understanding of the virus, and provide data needed to understand the true prevalence and impact of the virus.

Concluding comments.
The focus of our comments is the personal long-term impact on the families we support. However, it is important to acknowledge the cost of the virus to society. The charity previously commissioned an economic analysis of the cost of congenital CMV and the estimated cost over the year researched was £732 million. This was considered to be a conservative estimate and 40% of the total was the direct cost to the health, social and education services. The remainder was the cost to the wider economy of managing long term impairments. The cost of hearing loss (SNHL) was estimated to be £130 million. Whilst the figures are based on a decade ago, these costs are likely to have risen substantially. (Retzler et al. Economic Cost of congenital CMV in the UK. Arch Dis Child 2019). The cost of a universal screening programme must be minimal in comparison.

Introducing screening for cCMV directly addresses the National Maternity and Neonatal Investigation's aims of reducing preventable harm and improving safety across maternity and neonatal services for vulnerable patients during the critical perinatal period.

The UK now lags behind other countries who have introduced screening. It is unacceptable to wait another three years to look at this again. Where the NSC has identified gaps in evidence, we urge them to ensure this research is appropriately funded and prioritised, for example through the NIHR Health Technology Assessment programme, and we would be happy to assist with public and patient involvement aspects of any resulting research studies.

There is increasing evidence from the USA, Israel and Canada on screening neonates and we urge the committee to consider this new data along with more recent data on treatment and hearing outcomes. There have been a number of studies and implementations of screening over recent years and a reliable test, but our conclusion is that parents remain in a position where professionals lack awareness and timing of diagnosis is critical.

Overall, we are disappointed that the public and families are only being consulted at this stage, instead of the patient experience being part of the evidence presented. As a result, the evidence given shows a lack of consideration of the practicalities and inequalities within current care pathways for cCMV, and the impact on families. The analysis of NSC responses from 2022 (Greiner et al.) noted that responses were framed in terms of views of screening rather than describing experiences more generally. This is a limitation of this consultation four years later, as the emotional, psychological and personal cost to families should be the starting point. Rather than inviting their response to a lengthy document, the lived experiences of families should have been included. As mentioned previously, this consultation is not accessible to a lay audience, and not a meaningful way of gaining insight into patient and family experience.

We have no confidence that a baby born with the virus today will be in a better position than one born when the charity started supporting families in 2012. Whether a baby is tested, offered treatment and monitored is determined by awareness and practices where they are born. This is inequitable and unfair and causes harm. We urge the NSC to look at this matter with the urgency it deserves and place more emphasis on the patient viewpoint and lived experiences of those we support.

Name: Professor Hermione Lyall
Email: XXXX XXXX
Organisation: Imperial College Healthcare NHS Trust
Role: Paediatric Infectious Diseases Consultant (retired)

Publish submitter's name: True
Publish Organisation name: True

Condition: Cytomegalovirus

Combined response to the public consultation on the UK NSC external review on Congenital cytomegalovirus, 2025.

Compiled by Hermione Lyall on behalf of the seven national bodies listed below (XXXX XXXX).

British Paediatric Allergy, Immunology and Infection Group (BPAIIG)
President – Dr Jonnie Cohen

UK Congenital CMV Infection Collaboration (UKCCIC)
Leader – Dr Helen Payne

Congenital Infection, Education and Treatment (CONCEPT)
Leader – Dr Eleni Nastouli

British Association of Audiovestibular Physicians (BAAP)
President – Dr Shankar Rangan

British Association of Paediatricians in Audiology (BAPA)
Chair – Dr Jo Harris

National Deaf Children's' Society (NDCS)
Chief Executive Officer – George Crockford

British Academy of Audiology (BAA)
President – Dr Claire Benton

As paediatric infectious diseases specialists, obstetricians, virologists, midwives, audiologists, audio-vestibular physicians, paediatricians working in Audiology and members of the NDCS, from across the UK, we strongly support the National Screening Committee for commissioning this systematic review to assess 4 key questions in relation to universal / targeted neonatal screening for congenital CMV (cCMV).

1. What is the diagnostic accuracy of CMV testing of saliva in newborns?
2. What is the diagnostic accuracy of CMV testing of dried blood spots (DBS) in newborns?
3. What tests in newborns with CMV identify those likely to suffer long-term health consequences from cCMV, and who would benefit from prompt treatment?

4. Can a screening programme for cCMV reduce the burden of cCMV-related morbidity and mortality?

We recognise and commend the thorough and efficient way the review was undertaken, and the opportunity for some of us, as interested parties to interact with the excellent team of reviewers. Please see below our considerations regarding the findings for each key question.

Questions 1 and 2: What is the diagnostic accuracy of CMV testing of saliva / DBS?
It is reassuring to see that the reviewers have found that current evidence regarding diagnostic CMV DNA PCR on blood (DBS), saliva or urine is robust, and criteria 7 for a screening diagnostic test is fulfilled: thus, there are effective laboratory test options available.
Implementation of the appropriate test within current UK neonatal healthcare pathways will require pilot studies which assess: cost, efficiency, and acceptability to parents and staff, and we believe these need to be undertaken as soon as possible.

Question 3: What tests in newborns with cCMV identify which are likely to suffer long-term health consequences from cCMV, and who would benefit from prompt treatment?
The reviewers have outlined the problems with most of the studies which have currently investigated this question – with insufficient numbers, controls, or duration of follow up. From the studies assessed, the potential prognostic usefulness of brain MRI imaging, CSF studies, and blood CMV viral load have been highlighted. Indeed, the Alarcon brain imaging score (which combines findings in cranial US scan and MRI) is clinically highly predictive of long-term sequelae, and within Europe this scoring system is increasingly used for infants under investigation for cCMV (1, 2).
We fully agree with the reviewers' suggestion that a broader baseline multi-factorial risk scoring system for long-term sequelae is required, which takes into account: timing of fetal infection; neonatal clinical signs / symptoms; blood tests, including CMV viral load; sensory neural hearing loss (SNHL); and brain imaging. Combined epidemiolocal assessment of current international data sets is required to optimise prognostication for sequelae. Additionally, in future, it is likely that neonatal immunological responses to CMV, as well as other potential genetic factors may contribute to scoring for long-term sequelae. This scoring system should be based on studies which follow children at least until school entry so that late onset-SNHL, communication and learning are included in the outcomes.
As the reviewers have pointed out, randomised follow up studies are difficult to undertake for this condition, and outcomes of universal screening programmes in Canada, Israel and the USA, are now being reported. Requests for UK specific data/randomised controlled studies will delay implementation of screening in this country for another decade or more. For relatively rare

paediatric conditions, such as cCMV, well conducted studies undertaken in other countries with similar profiles to our own should be considered appropriate for assessing the case for neonatal cCMV screening in the UK.

Question 4. Can a screening programme for cCMV reduce the burden of cCMV-related morbidity and mortality?
This is the crux of the matter, and the evidence to date has significant problems. In particular the RCTs of valganciclovir treatment were undertaken in only a small number of symptomatic neonates, and modern brain imaging was not included as a criterion at baseline. Subsequent randomised studies of treatment in less severely affected infants did not complete, so we have no data to guide treatment for the majority of infants with cCMV, including those who may have minimal clinical signs at birth, but significant brain imaging and SNHL.
As the screening studies in Canada and Israel have demonstrated, clinicians are not good at diagnosing symptomatic cCMV. In Canada only 20% of clinically symptomatic neonates were diagnosed before the DBS PCR result was available. To understand the true picture of efficacy of antiviral interventions clinical trials need to be designed and undertaken in screened populations, across a wider range of severity, and including baseline brain imaging, rather than in only the most severely affected infants, diagnosed and referred to specialist centres.
We totally agree, that it must be demonstrated that as a consequence of screening benefit of diagnosis and treatment outweighs harm. Parents of infants with cCMV and prospective parents should be involved in the design of studies to assess the ethical questions and outcomes to be measured.
Of note, in our experience, parents of neonates with a potential new symptomatic cCMV diagnosis, universally express being let down by a health system which did not inform them about cCMV prior to pregnancy (3), nor the potential interventions, including: avoidance of CMV exposure antenatally, and antiviral treatment to prevent placental transmission etc (4, 5).

Consideration of Universal Neonatal CMV Screening or Extended Targeting cCMV Screening / Testing.
Although universal neonatal screening for cCMV is the only way to give all affected infants the opportunity for assessment, and if appropriate treatment, and this is what we advocate for, we wish to highlight that streamlined and effective extended targeting testing would still benefit a significant proportion of children with symptomatic cCMV born in the UK. This is diagnostic testing rather than screening, as these infants have been identified to be at significant risk of cCMV. Extended targeted testing should include infants:
1) Born to women where a risk of vertical CMV transmission has been identified antenatally.
2) Born with clinical signs and / or symptoms of cCMV.
3) Referred for audiological assessment from new-born hearing screening (NBHS).

Inequity of Diagnostic Provision for Infants with cCMV Across the Country.
As the NSC may be aware, currently the national programme for New Born

Hearing Screening (NBHS) is not aligned with the timeline for clinical assessment, diagnosis and treatment for cCMV. In particular, to confirm cCMV, diagnostic testing must be undertaken before 21 days of age, but audiological confirmation of SNHL is only mandated to occur within 4 weeks of the first hearing screening test (6). As the audiological assessment is often delayed beyond this time, many infants with cCMV are not diagnosed within the optimal treatment window. This was also highlighted in the recent critical national review of Paediatric Audiological Services (7). Please see the end of the document for an example of parental experience of the consequences of delayed testing for cCMV.

Clinical teams around the country are addressing this by training their hearing screeners to undertake CMV PCR saliva testing, within days of birth, at the time of referral for diagnostic audiological assessment (including: Bolton, Wirral, East of England, Devon, Southampton, West Kent, East Kent, Evelina, Imperial College Healthcare NHS Trust, Barts Health NHS Trust). This is highly feasible and is improving care pathways. Other centres have also focused on more timely referral to audiology, and CMV testing within the 21 day window (North Tyne) (8). The need for alignment is emphasised by a recent survey of audiology service providers which reported that timely CMV testing by hearing screeners occurred in only 27% of neonatal referrals for full audiological assessment (9).

Currently, there is serious inequity of diagnostic provision for infants with cCMV across the country. Support from the NSC to align audiological screening and testing with the cCMV diagnostic and treatment pathway would increase timely access to treatment, preventing late onset or progression of SNHL and reducing the need for hearing aids and cochlear implants. This would positively impact hearing, speech and language, and educational outcomes, as well as other neuro-developmental consequences in a significant number of children. We urge the NSC to address this harmful discrepancy in their final report.

Antenatal Screening for CMV

We look forward to the findings of the full systematic review of antenatal screening for CMV, as we believe that both antenatal and postnatal CMV testing must be considered in parallel.

Urgent Research Required into cCMV

As described on page 94 of the report, we urge the NSC to promote calls for research in this area, building on established links with the NIHR:

…The most substantial gap in the current evidence, where there is clear need for future clinical studies, is to properly compare the clinical impact of cCMV screening to current clinical practice without screening. Ideally this should consist of cluster randomised trials, where locations or medical centres are randomised to: universal cCMV screening, targeted screening after failing a newborn hearing screen, or standard practice without screening…

In our view, conducting cluster randomised trials, is very expensive in time, workforce and finance. It should be sufficient to learn from the very well conducted screening programmes underway in other countries, in order to

inform policy in the UK.
With the aim of prevention and / or amelioration of cCMV, further high-quality clinical research is required. Our relevant experts in the field would welcome the opportunity to meet with NSC and NIHR representatives to discuss the priority questions to address.

We believe that the following studies on cCMV are urgently required:
1) Regional pilot studies of implementation of antenatal and neonatal screening using a standardised approach – in order to “pool” outcomes.
2) Health economic studies of antenatal and neonatal screening and outcomes.
3) Social science evaluations of parental views and concerns regarding antenatal and neonatal screening.
4) Application of a baseline multi-factorial risk scoring system for long-term sequelae of cCMV, using prospectively collated data from CCMVNET, the international registry of children born with cCMV (ccmvnet.org).
5) Development of pathways for assessment of vestibular dysfunction in cCMV (currently significantly underdiagnosed).
6) Development of a European/US/International platform to facilitate clinical trials for cCMV considering different treatment options.

7) Bearing in mind that congenital syphilis and neonatal herpes simplex infections became HSA notifiable infectious diseases in 2025, we believe that cCMV should also be an HSA notifiable condition. This would improve UK specific epidemiological data, providing a better platform to monitor screening strategies

Conclusion
There is now increasing evidence from the US, Israel, and Canada on universal CMV screening of neonates and we urge the committee to reassess the evidence, based on this new data from countries with many similarities to our own. It has been shown to be feasible to do so on a large scale. There is also new data since the last consultation of hearing outcomes among infants treated with valganciclovir and better outcomes for these infants. Without screening, infants who are eligible for treatment are missed with consequent life-long harms.
France and Italy have very recently introduced screening in pregnancy as a national recommendation. This is based on the evidence of a significant reduction of transmission of infection to the foetus when primary infection is identified early. Without antenatal screening this is impossible.
Moderna has recently discontinued its programme to develop a CMV vaccine for the indication of congenital infection. Thus it is likely to be many years before a vaccine is available, so education and antenatal risk reduction is the only available strategy. There is evidence that knowledge of CMV serostatus allows women to assess their risk and make informed decisions about adopting risk reduction measures. Screening is needed to inform this. We urge the committee to further assess this new evidence for maternal and neonatal screening to reduce the lifelong harms to infants.

Additional notes on points of inaccuracy in the text
1) Introduction – the first symptom of cCMV listed is “renal disease” – this is incorrect, cCMV does not affect the kidneys. The hierarchy of symptomatology should be: brain damage, SNHL and inner ear disease, bone marrow suppression, in particular thrombocytopaenia, liver and biliary disease, and retinitis.
2) Page 13, line 29 – in fact transplacental transmission of CMV increases during pregnancy, and is much more likely in the third trimester (72%) than the first (24%). However, due to the teratogenic embryopathy of CMV, the outcome of first trimester infection is much more severe (10).
3) Page 91 – the suggestion of “treating symptoms as they emerge”, does not make clinical sense. Antiviral treatment has to be given as early as possible (ideally, within 30 days of life) to have an optimal effect. This is particularly important in terms of prevention of progression of SNHL and late- onset SNHL.
4) Page 162 – the Finnish study, which is referenced several times as a reason not to undertake neonatal screening is not applicable to the UK population, and this the study should not be cited in this way. As the reviewers have noted on page 162, the study is very small and cCMV is very rare in Finland. The most recent study of DBS in the UK gives a birth prevalence of cCMV of 0.66% (11).

Parental Experience of Outcome of a Positive CMV test in their infant with SNHL, at 8 Weeks of life, with Subsequent Unnecessary Investigations for cCMV and Parental Distress.
(parental consent obtained for this parental view to be submitted).
“As you know, xxx tested positive for CMV at 8 weeks old during investigations for the cause of his hearing loss, and from that moment for the next 4 weeks our lives were flipped upside down.
We went from enjoying our new bundle of joy to being petrified that he would suffer from long term health problems due to this disease.
We went from appointment to appointment, test to test and speaking to specialist departments that I’d never even heard of. It was emotionally and physically draining to go through and watch our precious baby boy do all of these tests to check if he had congenital CMV.
Thankfully all of the tests come back negative and we are so thankful for all the support and encouragement you and all of the other professionals involved gave us.
But, if we had one simple test before xxx was 3 weeks old, all of this wouldn’t have needed to happen. We wouldn’t have been dragged through this awful time as new parents and there wouldn’t have been the need to spend all the NHS money on all the tests undergone.
We are so strongly behind early testing for congenital CMV, not only to stop parents from having to go through what we went through but, to enable children to get treatment early enough if needed and save NHS money in the long run.”

References
1 Alarcon A et al. Neonatology. 2016;110(4):277-285. doi: 10.1159/000446690.
2 Alarcón A et al. Arch Dis Child Fetal Neonatal Ed. 2024 Feb 19;109(2):151-

158. doi: 10.1136/archdischild-2023-325790. PMID: 37739774; PMCID: PMC10894834.0
3 Greiner R, et al. J Health Serv Res Policy. 2025 Oct 9:13558196251382548. doi: 10.1177/13558196251382548. Epub ahead of print. PMID: 41065252.
4 Revello et al 2015 Aug 6;2(9):1205-10. doi: 10.1016/j.ebiom.2015.08.003.
5 Chatzakis C, et al Am J Obstet Gynecol. 18 juill 2023;S0002-9378(23)00470-2
6 Newborn hearing screening programme standards: valid for data collected from 1 April 2022 – GOV.UK.
7 Kingdon review of children's hearing services: final report – GOV.UK
8 Hagan AJ, et al Eur J Pediatr. 2025 Nov 11;184(12):747. doi: 10.1007/s00431-025-06612-9. PMID: 41214388; PMCID: PMC12602666
9 Raveendran et al, The Pediatric Infectious Disease Journal 2025, DOI: 10.1097/INF.0000000000004496
10 Enders G, et al. J Clin Virol. 2011 Nov;52(3):244-6. doi: 10.1016/j.jcv.2011.07.005. Epub 2011 Aug 5. PMID: 21820954.
11 Payne H et al Front. Pediatr. 13:1543132. doi: 10.3389/fped.2025.1543132

Name: xxxx xxxx

Email: xxxx xxxx

Organisation: British Association of Perinatal Medicine

Role: xxxx xxxx

Country: England

Subject: Congenital cytomegalovirus screening consultation submission

Apologies that we have missed the deadline for this but if our submission could still be considered for the consultation on congenital cytomegalovirus please can you pass this on.

The British Association of Perinatal Medicine (BAPM) is a professional association and registered charity. We are a membership organisation representing over 3,100 perinatal professionals and stakeholders including neonatal and obstetric doctors, nurses, ANNPs, midwives, managers, allied health professionals and parents. Our aim is to improve standards in perinatal care by supporting those involved to optimise their skills and knowledge, promote high quality, safe and innovative practice, encourage research, and speak out for the needs of babies and their families.
We welcome the very comprehensive report assessing newborn screening for congenital cytomegalovirus (cCMV) infection with a comprehensive appraisal of the viability, effectiveness and appropriateness of a screening programme. CMV infection is an important differential diagnosis for preterm and sick infants admitted to

neonatal intensive care. Distinguishing between cCMV and postnatally acquired CMV is important as acute treatment, likely long-term sequelae, follow-up and management pathways are very different.
Across the UK, there is variation in screening for cCMV, with some neonatal units in the UK routinely testing saliva on all preterm (e.g. less than 30 weeks gestation) on admission to the neonatal unit (followed by weekly swabs thereafter) versus other neonatal units that do not screen.
We welcome and support the recommendation for UK focused research studies to formally evaluate the impact of a cCMV screening programme and the other areas of recommendations for further research.

UK National Screening Committee

Name:	Peter Muir	**Email address:**	XXXX XXXX
Organisation (if appropriate):	UKHSA Clinical Network Laboratory Bristol		
Role:			
Do you consent to your name being published on the UK NSC website alongside your response?		**Yes**	~~**No**~~

Document section and page number	**Text or issue to which comments relate**	**Comment** *Please use a new row for each comment and add extra rows as required.*
Newborn screening systematic review		
Antenatal screening evidence map		
Page 6	**Summary**	It is surprising that the executive summary doesn't mention the extent of the problem of cCMV in the UK, as part of the justification (or not) of carrying out a review.
Page 6	**Lines 21-26**	Determination of CMV viral load in fetal blood may also be useful.
Page 9	**Lines 14-17**	In winter a large proportion of pregnant people will get an influenza like illness, and maybe more than once across pregnancy. If the illness is clearly URTI then no testing seems warranted (other than if influenza antiviral therapy is indicated), but where clinical

		uncertainty of cause exists, testing for CMV as a minimum becomes indicated. If this advice is given, the testing numbers will increase for an unknown outcome- that warrants a pilot.
Page 9	**Lines 19-22**	Evidence on the use of valaciclovir to prevent vertical transmission is limited to a single paper.
Page 9	**Lines 23-26**	A maximum 3 tests per antenatal patient would be required. However, with perfect uptake, that is a potential 900,000 tests per year- although some further pregnancies won't need screening as known IgG pos. The program would cost £millions on tests alone.
Page 9	**Lines 28-29**	There is no standardised accredited test we are aware of for amniotic fluid testing.
Page 10	**Lines 4-6**	The recommendation for amniocentesis if treatment with ACV is given seems counterintuitive.
Page 14-15	**Diagnostic accuracy studies**	In evaluating evidence on tests used to detect maternal CMV infection it is important to consider not only diagnostic accuracy but feasibility of routine diagnostic implementation in the UK NHS setting. While tests based on CMV DNA detection in serum or whole blood may have performed well, implementation of such tests in diagnostic laboratories may require a sample type (whole EDTA blood) which is not routinely available in the context of antenatal investigation, and would require establishment and validation of novel tests and a testing strategy which are not currently in place. Analysis based on CMV IgG only does risk missing some primary infections but is a cleaner assay.

Page 19	**Lines 1-2**	We agree that testing for maternal primary CMV infection will have a low PPV for cCMV, because not all primary maternal CMV infections lead to cCMV, and not all cCMV cases follow primary maternal CMV infection.
Page 22	**Studies of CMV assay accuracy**	The limitations of CMV serological assays are acknowledged. The highest sensitivity and specificity for detection of primary maternal CMV infection is likely to be achieved using testing strategies which include CMV IgG avidity testing, and those based on testing of sequential samples to detect maternal CMV IgG seroconversion. Serological diagnosis of non-primary maternal CMV infection is currently not possible.
Page 38	**Lines 6-19**	Another randomized study seems warranted. There is reasonable evidence that VACV reduces the rate of intrauterine transmission and the severity of fetal infection. Although there is wide experience in the use and safety of ACV in pregnancy, the VACV dose and duration used in these studies is considerably higher than that commonly used for treatment or prophylaxis of HSV and VZV infections in pregnancy. Few if any of the reviews and metanalyses considered here were designed or powered to evaluate the impact of pre-natal VACV exposure on post-natal follow-up of CMV-infected and uninfected infants. This should be included in future studies, and should involve at minimum a full clinical evaluation at birth and clinical, psychosocial and educational follow-up at 12 months and 5 years of age.

Page 48	**Lines 25-26**	In considering the merits of an antenatal screening programme, the Committee should also consider the alternative in the absence of a screening programme. This is likely to be the ad hoc testing for primary CMV infection in symptomatic women in early pregnancy, as currently recommended by RCOG: Congenital Cytomegalovirus Infection: Update on Screening, Diagnosis and Treatment - Khalil - 2025 - BJOG: An International Journal of Obstetrics & Gynaecology - Wiley Online Library. Having considered this and discussed with GPs, it is our opinion that this arrangement is unworkable. This would require education of antenatal patients to present in early pregnancy with symptoms compatible with primary CMV infection, and education of midwives and GPs on clinical diagnosis of, and testing for primary CMV infection, and referral to O&G services for treatment. This would cause considerable patient and clinician anxiety, and is likely to be difficult to establish as a national service, difficult to operate at a local level without a national framework, and challenging to communicate to midwives, GPs and antenatal patients. The review should therefore consider the relative merits of any proposed screening program when compared to such an alternative strategy. Our view is that a national screening program, if funded, would be preferable to the RCOG recommendation.
Page 49	**Lines 4-7**	Diagnostic accuracy studies should include CMV IgG avidity testing. How widely available are these tests, and what turn-around time can be delivered? ECCI recommends CMV PCR on serum for cases which are IgG negative, IgM positive. What is the sensitivity of this, and again, what is the current availability of validated PCR assays for serum testing, and their turn-around time?
Page 49	**Line 7**	There is considerable interest in testing saliva rather than urine in view of ease of sample collection; what is sensitivity/specificity, in

		particular, impact of breast milk contamination of saliva?
Page 49	**Line 8-9**	Whilst this would provide useful information, implementation of assay specific, program specific, test cut-offs different from that recommended by a manufacturer, it is problematic from an operational delivery and governance perspective.
Page 49	**Line 15**	It should be recognised that there are no long term follow up studies for mothers and children exposed to high dose valaciclovir in pregnancy.
Whole document		This review has been submitted by the Clinical Virology team, UKHSA Clinical Network Laboratory Bristol: Sowsan Atabani: sowsan.atabani@nbt.nhs.uk Andrew Bosworth: andrew.bosworth@nbt.nhs.uk Matthew Donati: matthew.donati@nbt.nhs.uk Stephanie Hutchings: stephanie.hutchings@nbt.nhs.uk Peter Muir: peter.muir@ukhsa.gov.uk

UK National Screening Committee

Name:	XXXX XXXX	**Email address:**	XXXX XXXX
Organisation (if appropriate):	XXXX XXXX		
Role:	**COO**		
Do you consent to your name being published on the UK NSC website alongside your response? **Yes** **No x**			

Document section and page number	**Text or issue to which comments relate**	**Comment** *Please use a new row for each comment and add extra rows as required.*
Newborn screening systematic review		
Page 32	**Question 2 – What is the diagnostic accuracy of cCMV testing of dried 1 blood spots (DBS) in newborns?**	We'd like to bring under your attention that our digitalMLPA technology might offer an affordable alternative for cytomegalovirus testing on dried blood spots. The main advantage is that digitalMLPA allows for simultaneous testing of SMA, SCID, CMV and over 25 other DNA based disorders that can be of interest for newborn screening. This includes confirmation of biochemical testing for disorders like HBA/HBB and CFTR. The selection of disorders can be adjusted for every country. The assay that we're currently developing uses only a single 3 mm DBS punch and does not require DNA purification. As a targeted, probe based technique, it lacks the privacy concerns that come with newborn sequencing. Moreover, the costs are at least ten times lower. Fabella T. et al (manuscript under review, *European Journal of Human Genetics),* describe results of testing DBS samples from 2,069 newborns using this digitalMLPA assay. The 78 CMV-specific probes were succesfully validated using artificial positive samples containing human DNA mixed with very low amounts of

		CMV virus. Testing on the 2,069 DBS samples produced convincing and reproducible results. We expect that our large CMV probe panel provides a more sensitive test as compared to qPCR-based assays. Please get in touch if you like to know more about digitalMLPA in newborn screening or if you are interested in collaborating on this topic. MRC Holland is a genetic testing company from The Netherlands, well known for developing MLPA, the gold standard for copy number detection. Moreover we are an experienced provider for newborn screening programmes for SMA – our IVDR certified MC002 assay is used as a first tier test in Poland and Serbia among others.