

# STATES OF JERSEY



## SUPPORT FOR PARENTS OF BABIES NEEDING ADDITIONAL NEONATAL CARE

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Lodged au Greffe on 27th June 2023  
by Deputy R.S. Kovacs of St. Saviour  
Earliest date for debate: 18th July 2023

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STATES GREFFE

## **PROPOSITION**

**THE STATES are asked to decide whether they are of opinion –**

that provision, including financial support, should be established to support parents who have preterm babies, or babies requiring neonatal care, and to request the Minister for Social Security to bring forward the proposals for this provision for approval by the Assembly prior to the end of June 2024.

DEPUTY R.S. KOVACS OF ST. SAVIOUR

## REPORT

*“No matter the length of stay, a neonatal experience can have a long lasting impact on the whole family.”<sup>1</sup>*

A baby born prematurely or a baby that requires extra neonatal care, needs additional time and care to develop as compared to a baby delivered at full term with no complications.

Those babies can also have problems with feeding or being breastfed, when especially during these early stages it is very important the breastfeeding to be done on demand for the mum to be able to continue breastfeeding if she chooses so, therefore her presence for a longer period and ongoing is crucial at this stage in keeping supply and the immunological benefits.

Although the latest update to the parental law has increased the leave available to new parents, a large part of that leave is unpaid, or paid at a lower rate than salary, and many parents feeling the financial pressure have to make the difficult choice to return to work in order to survive, although neither they or the baby are ready to be separated even temporarily.

This proposition is intentionally left open as to the mechanisms to be used. There are a number of different ways in which the intent could be achieved – however the policy team will be best placed to find the appropriate route.

From my perspective such a scheme should include a grant payment, along the lines of the paid parental allowance of £246.89 per week, run alongside existing unpaid leave, the criteria for application linking to how early the preterm baby was born and/or the length of stay in hospital, up to a maximum of 12 weeks.

The proposition asks the Minister to bring the scheme back to the Assembly for approval – ensuring that the Assembly retains final agreement that the scheme developed is appropriate and fit for purpose.

### Preterm babies

A preterm baby is defined as a baby born alive before 37 weeks of pregnancy are completed.

- [Births and Breastfeeding Profile 2022.pdf \(gov.je\)](#) - In 2022 57 births (7% of all live births) occurred before 37 weeks gestation and were classed as preterm.
- [Births and Breastfeeding Profile 2021.pdf \(gov.je\)](#) - In 2021 66 births (7% of all live births) occurred before 37 weeks gestation and were classed as preterm.

Paid parental allowance for Jersey is a weekly payment, paid in arrears. The birth mother must take 6 weeks immediately following the birth of their child. Whilst there is the option for parents to take a further 6 weeks – and indeed later a further portion of leave, what happens if a baby arrives early? Parental leave commences – and concludes, in the

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<sup>1</sup> [Statistics for babies admitted to neonatal units at full term | Bliss](#)

same time frame as if the child was born within the two weeks either side of their due date.

So, if a baby is born six weeks early, the first portion of parental leave is over before the baby was even due to arrive.

In addition, the situation for parents of preterm babies is not the same as for those born around their due date – the baby may have needed to stay in the Specialist Care Baby Unit (the “SCBU”) for long sections of that time, they may still have difficulties with feeding, or other more complicated requirements.

The [World Health Organisation](#) identifies some of these difficulties –

- **Staying warm:** Preterm babies lose body heat more easily, putting them at risk of life-threatening hypothermia. They need extra energy and care to stay warm and grow.
- **Feeding:** Preterm babies can have trouble feeding because the coordinated suck and swallow reflex is not yet fully developed. They may need additional support for feeding.
- **Breathing:** Many preterm babies start breathing on their own when they are born, but others need to be resuscitated. If the lungs are not fully developed and lack surfactant (a substance that helps keep the lungs expanded), preterm babies may have difficulty breathing. Sometimes, premature babies that start off breathing are not strong enough to continue on their own. They exhaust themselves and may stop breathing (apnoea).
- **Infections:** Severe infections are more common among preterm babies. Their immune systems are not yet fully developed, and they have a higher risk of dying if they get an infection.
- **Brain:** Preterm babies are at risk of bleeding in the brain, during birth and in the first few days after birth; about 1 in 5 babies weighing less than 2kg have this problem. Preterm babies can also have brain injuries from a lack of oxygen. Bleeding or lack of oxygen to the brain can result in cerebral palsy, developmental delays and learning difficulties.
- **Eyes:** Preterm babies’ eyes are not ready for the outside world. They can be damaged by abnormal growth of blood vessels in the retina. The condition is usually more severe in very premature babies and if they are given too-high a level of oxygen. This can result in visual impairment or blindness.

For parents experiencing the difficulties and complication caused by a preterm birth, the last thing they need to be concerned with is having to leave that baby and go back to work before the child has reached gestational due date.

## Neonatal care

In addition to preterm babies, this proposition seeks the same provisions to be made for parents of babies that require neonatal care. The word ‘neonatal’ refers to newborn babies, or those still in the first 28 days of life.

There are a variety of reasons why full-term babies need to be cared for on a neonatal unit.<sup>2</sup>

According to the Bliss-supported [NHS England programme](#), which looked at reducing the number of term admissions on to a neonatal unit, the five most common reasons were:

- [Respiratory conditions](#) (about 25 per cent of all term admissions)
- Infection (about 18 per cent of all term admissions)
- Hypoglycaemia - this is where a baby has low levels of glucose in their blood (almost 12 per cent of all term admissions)
- Jaundice (around 6 per cent of all term admissions)
  - 81 per cent of these babies received phototherapy
  - 33 per cent received intravenous fluids
  - 1.6 per cent received a blood transfusion
- [Asphyxia \(HIE\)](#) (2.5 per cent of all term admissions)

The same arguments made in relation to preterm babies apply to those undergoing neonatal care. Parents should be able to focus wholly on their child.

## Benefits to preterm and neonatal babies

In looking at this subject there are numerous articles and sources citing the benefits of early care – and the particular benefits to pre-term babies and neonatal babies. The following are extracts from just a few that are particularly relevant to the scope of this proposition.

The [WHO recommendations for care of the preterm or low-birth-weight birth](#) are intended to inform development of national and subnational health policies. A couple of pertinent recommendations are detailed as follows –

*Recommendation A.2 - Mother’s Own Milk - Mother’s own milk is recommended for feeding of preterm or low-birth-weight (LBW) infants, including very preterm (< 32 weeks’ gestation) or very LBW (< 1.5 kg) infants.*

*Recommendation A.9 - Duration of exclusive breastfeeding - Preterm or low-birth-weight infants should be exclusively breastfed until 6 months of age.*

*Recommendation C.4 - Parental leave and entitlements should address the special needs of mothers, fathers and other primary caregivers of preterm or low-birth-weight infants. (Good practice statement)*

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<sup>2</sup> [Statistics for babies admitted to neonatal units at full term | Bliss](#)

[Special care: ill or premature babies](#) - NHS ([www.nhs.uk](http://www.nhs.uk)) refers to various factors with some excerpts shown below –

- Touching and Holding your baby – “Your baby will benefit greatly from physical contact with you. You can talk to your baby as well – this can help both of you”.
- Feeding - “Your milk has particular benefits, especially if your baby is sick or premature, as it's enriched with proteins (such as antibodies), fats and minerals”.
- Incubators – “Some incubators have open tops, but if your baby's incubator does not, you can put your hands through the holes in the side of the incubator to stroke and touch them”.

### **UK Neonatal care (Leave and Pay) Act**

This proposition is far from unusual – for instance in the UK the Neonatal care (Leave and Pay) Act received Royal Assent on 24 May 2023<sup>3</sup>.

The Neonatal Care (Leave and Pay) Act has been introduced to provide additional leave and pay for employees with responsibility for children receiving neonatal care. For parents who meet the qualifying criteria, it will offer up to 12 weeks of extra leave and pay. This provides vital time with their babies if they are born premature or sick without the worry of returning to work.<sup>4</sup>

The qualifying criteria for the UK leave scheme are -

- You meet the minimum service and earning requirements
- You are an employee
- Your baby is cared for in a health setting for more than 1 week before they reach 28 days of life

### **Conclusion**

As previously noted this proposition does not seek to prescribe how the Ministers design and implement such a scheme, but the recent application of this bill may be of use.

*The important benefits to preterm babies and with additional need for neonatal care of early on-going contact with parents are well known and are better highlighted further in the CRIA part of the report- developing and getting healthier much quicker are just to name a couple.*

In conclusion, having a preterm baby is not a choice – in order to give preterm children the best start in their lives we can take a small step to easing some of the difficulties encountered by their parents, as additional financial pressures arising.

As a quote from Stuart C McDonald MP for Cumbernauld, Kilsyth and Kirkintilloch East rightly mentioned in relation to the related legislation newly approved in the UK,

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<sup>3</sup>[Research briefing - Neonatal Care \(leave and pay\) Bill 2022-23: Progress of the Bill](#)

<sup>4</sup>[Neonatal Leave and Pay Campaign | Bliss](#)

*“No parent should have to choose between being with their premature or sick baby in neonatal care and having to return to work to earn a living; or enjoying the full benefits of parental leave and going back to work”<sup>5</sup>.*

This is not a huge change – it will affect only a very small percentage of the population. But for those affected, it will make a big difference.

## **Financial and Manpower Implications**

In Jersey the current Parental Allowance rate is £246.89 p/w which is the figure used below to estimate the cost of introducing a neonatal payment. In the UK neonatal payments can be paid for a maximum of 12 weeks which is considered not unreasonable and is used as the maximum number of weeks in Jersey.

Maximum neonatal allowance in Jersey that an individual could claim = £2,962.68

### **For Preterm –**

In 2021 - 66 preterm babies which would result in a total payment = £195,536.88

In 2022 - 57 preterm babies which would result in a total payment = £168,872.76

The above provides an estimate for the maximum annual payments in 2021 and 2022 based on payments for 12 weeks in every case which is unlikely. For increased accuracy, the following UK data is used on length of prematurity –

Of the births that were preterm in the England and Wales in 2021:

- 6% were extremely preterm (before 28 weeks)
- 10% were very preterm (between 28 and 31 weeks)
- 83% were moderately preterm (between 32 and <37 weeks).

Therefore for 2022 the potential payment is estimated as follows -

- 83% = 47 (approx.) = 47 x (£246.89\*5weeks) = £58,019.15
- 16% = 9 (approx.) = 9 x (£246.89\*12weeks) = £26,664.12
- Total = £84,683.27

### **Neonatal**

It is even harder to estimate costs relating to neonatal admissions. Whilst the maximum 12 weeks would still apply, the time in hospital would fluctuate – some babies only requiring a few days or a week of neonatal care.

Applying the latest available data on neonatal admission in the UK (data from 2016), approximately 13% of all live births required neonatal care. If we apply this percentage against the Jersey 2022 figure, less the already calculated preterm of 8% of births, we generate a figure of 5%, equating to 42 babies – a maximum (and very unlikely) expenditure of £124,432.60.

These are the maximum estimates, based on all preterm or neonatal babies requiring the maximum time in care – in reality the likely expenditure would be considerably lower.

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<sup>5</sup> <https://www.gov.uk/government/news/parents-whose-babies-require-neonatal-care-to-receive-paid-leave-under-new-law-backed-by-government>

## Appendix (Other resources)

### *Parental Leave in Jersey (Employment Law)*

The following provide details of the current position regarding parental leave under Jersey law -

- [Guidance Note 13 - Parental Rights | JACS](#) - incorporates Employment (Amendment No.11) (Jersey) Law 2020
- [2020-parental-leave-booklet.pdf \(jacs.org.je\)](#) – this refers to the relevant sections of the [Employment \(Jersey\) Law 2003 \(jerseylaw.je\)](#).
- [Employment \(Jersey\) Law 2003 \(jerseylaw.je\)](#) - Part 5A deals with Parental rights

Excerpt from the above law -

#### *Article 55D Entitlement to parental leave*

*(6) The “entitlement period” means the period which –*

- (a) begins no earlier than the beginning of the 11th week before the week in which childbirth, or placement for adoption, is expected to occur; and*
- (b) ends on –*
  - (i) the date which is 2 years from the date of childbirth or placement for adoption, or*
  - (ii) the date on which the employment terminates, whichever is the sooner.*



# Child Right Impact Assessment

Impact Assessment by Raluca Kovacs

## STAGE 1: SCREENING

<b>Question 1: Name the measure / proposal and briefly describe its overall aim</b>
That provision, including financial support and additional employment leave, should be established to support parents who have preterm babies, or babies requiring neonatal care, and to request the Minister for Social Security, in consultation with the Minister for Children and Education, and the Minister for Health and Social Services, to bring forward the proposals for this provision for approval by the Assembly prior to the end of June 2024.
<b>Question 2: What children's rights does it impact upon?</b>
<p><i>Article 3</i> The best interests of the child must be a top priority in all things that affect children.</p> <p><i>Article 4</i> Governments must do all they can to make sure every child can enjoy their rights.</p> <p><i>Article 6</i> Every child has the right to life. Governments must do all they can to ensure that children survive and develop to their full potential.</p> <p><i>Article 7</i> Every child has a right to be registered at birth, to have a name and nationality, and, as far as possible, to know and be cared for by their parents.</p> <p><i>Article 9</i> Children must not be separated from their parents against their will unless it is in their best interests (for example, if a parent is hurting or neglecting a child). Children whose parents are separated have the right to stay in contact with both parents unless this could cause them harm.</p> <p><i>Article 18</i> Both parents share responsibility for bringing up their child and should always consider what is best for the child. Governments must support parents by giving them the help they need, especially if the child's parents work.</p> <p><i>Article 24</i> Every child has the right to the best possible health. Governments must work to provide good quality health care, clean water, nutritious food and a clean environment so that children can stay healthy. Richer countries must help poorer countries achieve this.</p> <p><i>Article 26</i> Every child has the right to benefit from social security. Governments must provide social security, including financial support and other benefits, to families in need of assistance</p> <p><i>Article 27</i> Every child has the right to a standard of living that is good enough to meet their physical, social and mental needs. Governments must help families who cannot afford to provide this. For this to happen they should have access to adequate housing.</p>

<b>Question 3: What children and young people will be affected?</b>
All babies that are born preterm or requiring neonatal care
<b>Question 4: What is the likely impact of the proposal / measure on children?</b>
Potential to ensure improved health and wellbeing by greater parental care after birth.
<b>Question 5: Is a full child rights impact assessment required? Explain your reasons</b>
Yes. The impact on children’s rights is considerable. This proposition will provide the financial support to allow parents greater involvement with their baby at a time when the baby is at its most vulnerable. This support will also alleviate the stress of having to juggle work with hospital visits.

**If a full child rights impact assessment is required proceed to stage 2**

## **STAGE 2: SCOPING (Background and Rights Framework)**

<b>Question 6: Name the measure / proposal being assessed and describe the overall aim</b>
That provision, including financial support and additional employment leave, should be established to support parents who have preterm babies, or babies requiring neonatal care, and to request the Minister for Social Security, in consultation with the Minister for Children and Education, and the Minister for Health and Social Services, to bring forward the proposals for this provision for approval by the Assembly prior to the end of June 2024.

<b>Question 7: Which human rights instruments and articles are relevant to the measure / proposal?</b>		
Human Rights Instrument	Article	Further analysis on the expected / actual effect
UNCRC	Article 3	<i>The best interest of the child must be a top priority in all things that affect children.</i>  The Government has vowed to Put Children First. By actively providing additional financial supporting for parents of preterm and neonatal babies it will be taking an active step to prioritise their health and wellbeing.
UNCRC	Article 4	<i>Governments must do all they can to make sure every child can enjoy their rights.</i>  As per Article 3 above

UNCRC	Article 6	<p><i>Every child has the right to life. Governments must do all they can to ensure that children survive and develop to their full potential</i></p> <p>As per Article 3 above</p>
UNCRC	Article 7	<p><i>Every child has a right to be registered at birth, to have a name and nationality, and, as far as possible, to know and be cared for by their parents.</i></p> <p>As per Article 3 above with emphasis being placed on the importance of being cared for by both their parents</p>
UNCRC	Article 9	<p><i>Children must not be separated from their parents against their will unless it is in their best interests (for example, if a parent is hurting or neglecting a child). Children whose parents are separated have the right to stay in contact with both parents unless this could cause them harm.</i></p> <p>The additional financial support will ensure that parents are not separated from their babies and can have the maximum amount of contact with them within the medical setting.</p>
UNCRC	Article 18	<p><i>Both parents share responsibility for bringing up their child and should always consider what is best for the child. Governments must support parents by giving them the help they need, especially if the child's parents work.</i></p> <p>The introduction of this financial provision will allow both parents to remain greatly involved with their baby and be equally available.</p>
UNCRC	Article 23 ?	<p><i>A child with a disability has the right to live a full and decent life with dignity and, as far as possible, independence and to play an active part in the community. Government s must do all they can to support disabled children and their families.</i></p> <p>Disabilities may result from a preterm birth and the financial provision is a step towards</p>

		providing parents with the flexibility to spend time with the medical profession to discuss how to deal with any disability.
UNCRC	Article 24	<p><i>Every child has the right to the best possible health. Governments must work to provide good quality health care, clean water, nutritious food and a clean environment so that children can stay healthy.</i></p> <p>Introduction of this provision will ensure that the babies get the best start in life</p>
UNCRC	Article 26	<p><i>Every child has the right to benefit from social security. Governments must provide social security, including financial support and other benefits, to families in need of assistance</i></p> <p>The introduction of this provision will be a step towards greater financial security for parents during the period when a child is in hospital.</p>
UNCRC	Article 27 ?	<p><i>Every child has the right to a standard of living that is good enough to meet their physical, social and mental needs. Governments must help families who cannot afford to provide this. For this to happen they should have access to adequate housing.</i></p> <p>The introduction of this provision will assist with ensuring that the needs of the child can be met.</p>

### STAGE 3: EVIDENCE

<b>Question 8a: What quantitative evidence have you used to inform your assessment? What does it tell you?</b>			
Evidence collected	Evidence source	Explanation of the importance	What are the data gaps, if any?
66 preterm babies were born in Jersey in 2021	<a href="#">Births and Breastfeeding Profile 2022.pdf (gov.je)</a>	Establishes that 7% of all live births in Jersey were preterm	Click or tap here to enter text.

57 preterm babies were born in Jersey in 2022	<a href="#">Births and Breastfeeding Profile 2022.pdf (gov.je)</a>	Establishes that 7% of all live births in Jersey were preterm	Click or tap here to enter text.
Statistics relating to UK preterm babies	<a href="#">Premature birth statistics   Tommy's (tommys.org)</a>	Provides comparison with UK statistics on preterm births	
Study involving 26 hospitals and nearly 1,800 babies	<a href="#">Premature babies healthier when parents help with hospital care, study shows   Premature birth   The Guardian (7 Feb 2018)</a>	Premature babies do better if their parents are allowed to help care for them in hospital alongside nurses, rather than being treated as visitors and left on the sidelines.	
Systematic review included 124 studies	<a href="#">Kangaroo Mother Care and Neonatal Outcomes: A Meta-analysis   Pediatrics   American Academy of Pediatrics (aap.org)</a>	<i>“Compared with conventional care, kangaroo mother care was associated with lower mortality, lower risk of neonatal sepsis, hypothermia, hypoglycaemia, hospital readmission and exclusive breast feeding. Newborns receiving kangaroo mother care also showed improved vital signs for respiratory rate, pain measures, oxygen saturation, temperature and head circumference”.</i>	

<b>Question 8b: What key missing information / evidence would have been beneficial to your analysis?</b>
Data showing the split in preterm births in terms of extremely preterm (before 28 weeks); very preterm (between 28 and 31 weeks) and moderately preterm (between 32 and less than 37 weeks)
Data showing a comparison between babies that have received unlimited parental care and those babies whose parents have limited time with their babies due to work constraints

Question 9a: What qualitative evidence have you used to inform your assessment? What does it tell you?		
Evidence collected	Evidence source	Explanation of the importance
<i>“There is a clear moral case for parents of premature babies to have day one rights to additional leave, given the difficult circumstances they face.”</i>	Response to Question 6 in a submission from the British Medical Association which was  “Do you agree that Neonatal Leave should be a ‘day one right’ in line with Maternity Leave, Adoption Leave and Parental Bereavement Leave?”  <a href="#">bma-consultation-response-neonatal-pay-oct-2019.pdf</a>	The statement is self-explanatory.  No parent should have to choose between having to go to work or being with their baby who is in special care.
<i>“Preterm babies are at risk of developing disabilities that will affect them for their entire lives. The extent to which this will affect their life strongly depends on how early they were born, the quality of care they received during and around birth and the days and weeks that follow”.</i>	<a href="#">Newborn health: Challenges facing preterm babies (who.int)</a>	Identifies the challenges facing preterm babies and the areas where special care may be required
<i>“Touching and Holding your baby – “Your baby will benefit greatly from physical contact with you. You can talk to your baby as well – this can help both of you”.</i>  <i>“Feeding - “Your milk has particular benefits, especially if your baby is sick</i>	<a href="#">Special care: ill or premature babies - NHS (www.nhs.uk)</a>	Illustrates the importance of the parental care and involvement in the very important days after birth

<p><i>or premature, as it's enriched with proteins (such as antibodies), fats and minerals".</i></p> <p><i>"Incubators – Some incubators have open tops, but if your baby's incubator does not, you can put your hands through the holes in the side of the incubator to stroke and touch them".</i></p>		
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<p><b>Question 9b: What key missing information / evidence would have been beneficial to your analysis?</b></p>
<p>Discussions with parents who have experienced a preterm birth or babies in neonatal care about their experiences and their involvement in their baby's care</p>
<p>Further discussions with parents to establish the financial ramifications and issues arising during their baby's time in special care unit</p>

**STAGE 4: SCRUTINISING CHILDREN'S INVOLVEMENT**

<p><b>Question 10: Has evidence from third party consultations with children and young people been considered in the development of the proposal or measure?</b></p>			
Groups consulted	Source of Information	Please provide a brief description of process	What were the findings?
No groups have been consulted.	Click or tap here to enter text.	Click or tap here to enter text.	

<p><b>Question 11: What groups of children and young people have been directly involved in developing the proposal or measure?</b></p>			
Groups involved [✓ if those affected by the proposal]		How were they involved	What were the findings
No children or young people have been directly involved in	✓	Click or tap here to enter text.	Click or tap here to enter text.

developing this proposition			
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**STAGE 5: ASSESSING THE IMPACT**

<b>Question 12: What impact will (or does) the proposal or measure have on children and young people's rights</b>		
Type of impact <i>[please highlight]</i>	Justification for Argument	likely or actual short/medium/long-term outcomes
Positive	Increases parents availability to be at the hospital with their baby and speak to medical staff	Improves understanding of the medical issues facing the baby
Positive	Increase the bonding time for both parents and their ability to care for their baby	It will ensure that babies preterm and neonatal babies will have the best possible start in life by enabling both parents to have the maximum involvement in their care.
Positive	Increases the length of time a baby can be breastfed	Benefits of breastfeeding

<b>Question 13: Will there be (or are there) different impacts on different groups of children and young people?</b>		
Group of children affected	Initial analysis of the positive impact on rights	Initial analysis of the negative impact on rights
There may be a greater impact on babies born to middle income parents i.e. those who are above the Income Support threshold	<ul style="list-style-type: none"> <li>- Improving health of babies</li> <li>- Relieving financial pressures</li> <li>- Reducing stress for parents</li> <li>- Allowing greater time to bond with babies</li> </ul>	None

<b>Question 14: If a negative impact is identified for any area of rights or any group of children and young people, what options are there to modify the proposal or measure to mitigate the impact?</b>	
Negative impact	What options are there to modify the measure(s) or mitigate the impact?
No negative impacts identified	Click or tap here to enter text.



## STAGE 6: CONCLUSIONS AND RECOMMENDATIONS

**Question 15: In summary, what are your key findings on the impact of the measure or proposal on children and young people's rights?**

The proposition will have a positive effect on the rights of those children born prematurely or requiring neonatal care by giving them the best possible start in life.

## STAGE 7: PUBLISH CRIA

**Question 16: Should the full assessment or a summary be published? Will a child-friendly version be produced?**

Yes, this CRIA will be published

## STAGE 8: MONITOR & REVIEW

**Question 17: Have the recommendations made in Stage 6 been acted upon?**

Pending the results of this debate

**Question 18: Where recommendations have not been acted upon, is further action required?**

Click or tap here to enter text.