

# **Young Patients Family Fund**

**CRWIA – Stage 3**

**March 2023**

## CRWIA – Stage 3

### Publication Template

#### CRWIA for a non-legislative policy/measure

CRWIA title: Young Patients Family Fund Publication date:	
Summary of policy aims and desired outcomes	<p>The Young Patients Family Fund aims to remove some of the financial barriers for families visiting a baby, child or young person in hospital. It will do this by allowing parents, carers and/or siblings (aged under 18) to claim some of the costs associated with visiting a young inpatient in hospital.</p> <p>The desired outcome of the fund is that more families can visit child inpatients more often and improve impact of a hospital stay on baby, child or young person.</p>
Executive summary	<p><u>Overview</u></p> <p>The Young Patients Family Fund will help to offset the cost of travelling to and from hospital during a child or young person's stay in hospital and the subsistence required to allow claimants to spend time to support the health and wellbeing of the child or young person.</p> <p>Specifically the fund will support parents, carers and/or siblings to cover the cost of travel, subsistence and (in some instances) accommodation associated with visiting a child inpatient under 18 in line with the UNCRC definition of a child.</p> <p>This includes:</p> <p>Travel: Claimants are expected to use the most cost effective, reasonable means of transport. Public transport costs can be reimbursed in full for up to one return journey per day for each claimant on production of receipts. Contributions towards the cost of fuel will be reimbursed at the current mileage rate which is based on the HMRC Fuel Advisory Rate per mile for up to one return car journey per day for each claimant, when they are travelling to the hospital separately on the same day and any accompanying sibling(s) up to the age of 18. If all travel together, only one return journey should be claimed.</p>

Only standard class travel can be reclaimed.

#### Taxi Fares

Travel by taxi should be seen as last resort and reimbursement will only be considered in certain circumstances e.g. no public transport availability or subject to a visitor's medical condition.

Taxi travel must be approved by clinical staff prior to journey. Where approved, taxi travel will be reimbursed in full on the submission of receipts for one return journey per day.

#### Flights

Air travel should only be considered where it is cheaper than other forms of transport or where other forms of transport are not reasonable (e.g. island to mainland travel).

Flights must be approved by NHS Board prior to travel. Approved flights are limited to a maximum of one return journey by air per week for each eligible visitor.

#### Meals and Subsistence:

Claims for meals may be made by one of the following means:

- A contribution up to a limit of £8.50 per day per eligible visitor for food and non-alcoholic beverages. This may be purchased outside of hospital grounds. No receipts are required for the purposes of being reimbursed for meal costs however, claimants must only submit claims for their actual spend on food and non-alcoholic beverages where costs are below £8.50 per day. For example, if a claimant spends £5.50 on food then they should only claim £5.50 and not £8.50.

or

- Meals may be directly provided free of charge for eligible visitors by the hospital (e.g. staff canteen or patient meals) up to a maximum of three meals per day.

or

- Meal tokens or vouchers may be directly provided to eligible visitors to be used in a hospital canteen or similar. Eligible visitors are not permitted to claim for the cost of food if the hospital provides meals free of charge or meal tokens.

However, in instances where the hospital can provide either monetary reimbursement for meals or free hospital meals, eligible visitors can decide which option is preferable to them.

#### Accommodation:

NHS boards may have accommodation available to claimants if required and this should be accessed in the first instance. In the exceptional circumstance where hospital accommodation is not available, a contribution to reasonable overnight accommodation costs will be reimbursed for the duration of

eligibility. This should be booked, where possible, in advance by the Health Board. Reasonable is defined as the most cost effective accommodation available.

#### Impact of the fund on children's rights and wellbeing

There was evidence of the impact of the financial cost to families of visiting children and young people in hospital. It was also clear that while all families would benefit from financial support particular groups faced extra challenges:

Children in poverty, disadvantage – as their parents may not be well placed financially to frequently visit them should they be admitted to hospital.

Children with disabilities or additional support needs (accessibility) – as they may be more likely to spend time as a hospital inpatient

Children living in remote or rural areas –the cost of visiting a hospital a long way from home.

There was evidence that public transport may not be appropriate for children with weakened immune systems or a disability and other forms of travel prohibitive so the Fund will allow use of taxis where appropriate.

Families may lack the money to cover unexpected extra costs associated with their child being in hospital. The Fund will ensure that the cost of visiting a young inpatient will be subsidised so that it is possible for families to visit as often as needed. Access to reimbursement should be made as soon as practicable in an effort to ensure that the family is not out of pocket for longer than their finances can support.

Children with disabilities may have numerous appointments which may not be classed as an inpatient stay but which add up to many visits which impact on family finances. Claims for travel costs associated with outpatient visits can be made through the NHS Patient Travel Reimbursement Scheme. This scheme means that children up to the age of 16 (or up to 19 if in full time education) can apply to have their own travel costs and those of an escort (such as parent/carer) covered when attending outpatient appointments. The reimbursement is automatic for children living in the highlands and islands but is means tested elsewhere in Scotland. The Travel Reimbursement Scheme does not cover subsistence or accommodation costs associated with outpatient appointments.

	<p>Transport in remote and rural areas can be limited and expensive so some families may need to access funding for transport and also accommodation. The Fund will not have a cap on the amount that can be claimed. In addition, reimbursement through the NHS Patient Travel Scheme is automatic for children living in the Highlands and Islands. The Highlands and Islands Patient Travel Scheme was set up in recognition of the difficulties and expense involved in travelling to and from hospital for people resident in remote mainland and island communities. This scheme is intended to reimburse part of the patient's travelling expenses on the grounds of the distance which must be travelled to UK hospitals for NHS treatment or appointments.</p> <p>Siblings of the inpatient may be disadvantaged if the fund does not cater for them. Siblings can provide emotional care and support to a child inpatient in a similar way to parents or primary carers. In addition, parents may struggle to attend hospital if they have little or no childcare available for other children resident at home. The initial scope of the Fund has therefore been widened to include siblings under 18.</p>
Background	<p>A commitment was made with the SNP First Steps 2021 manifesto document to:</p> <p>“Establish the Young Patients Family Fund to support families visiting children who are receiving inpatient care”.</p> <p>The Young Patients Family Fund will help to offset the cost of: travelling to and from hospital during a child or young person's inpatient stay; the subsistence required to allow claimants to spend time at the hospital; and any accommodation required by eligible visitors.</p> <p>Eligible claimants under the fund are parents, primary carers and/or siblings (under 18) of the young inpatient (also aged under 18).</p> <p>Eligible claimants can claim for:</p> <ul style="list-style-type: none"> <li>the cost of one return journey to the hospital per day by public transport (standard class only);</li> <li>the cost of one return flight per week per eligible visitor when flying is deemed an appropriate mode of travel e.g island to mainland visit.</li> <li>the cost of motor mileage for one return journey to the hospital per day;</li> <li>the cost of subsistence while visiting provided as one of the following:</li> </ul>

	<p>a flat rate contribution of up to £8.50 per person, per day for food and non-alcoholic beverages;  up to 3 meals per day provided directly to the eligible visitor;  or  meal tokens provided to the eligible visitor to be used in the hospital canteen or similar.  a contribution to reasonable overnight accommodation costs where the hospital cannot provide their own accommodation.</p>
<p>Scope of the CRWIA, identifying the children and young people affected by the policy, and summarising the evidence base</p>	<p>All babies, children and young people under the age of 18 will be affected by the policy as all have the potential to experience an inpatient stay in hospital.</p> <p>It will enable families to visit regularly to provide vital support to their children and be active partners in their child's health care (Articles 2, 3, 6, 12, 18(1,2,3), 23, 24 of the UNCRC). It will help to maintain emotional ties between the child and their parents, carers and/or siblings while they are undergoing treatment in hospital. It will reduce the financial burden for a family with a child in hospital (article 27 (1-3) of the UNCRC).</p> <p>Evidence highlighted that visiting a sick child in hospital can be a financial burden and added stress for families at a difficult time. Recommendations associated with relevant evidence have included a scheme of assistance for families. Research with parents of children with disabilities found continued difficulties in accessing support and resources</p> <p>Similarly the Royal College of Paediatric and Child Health report <i>Poverty and Child Health 2017</i> <a href="https://www.rcpch.org.uk/sites/default/files/2017-12/RCPCH%20Poverty%20and%20Child%20Health%202017.pdf">pdf RCPCH.pdf (cpag.org.uk)</a> found that when children are sick, poverty makes things worse. It emerged very strongly from doctors' comments that not only does poverty have an effect on children's health, but when a child is sick or disabled then poverty makes it more difficult for them to get the care and support they need. The cost of transport and fear of losing money (or even losing their job) by taking time off work can make it difficult for parents to bring their children to appointments, especially when they have ongoing conditions that require frequent attendance at hospital.</p> <p>Evidence also highlighted that for some parents and carers household income had reduced because of the COVID 19 pandemic.</p> <p>The nearest existing financial scheme is the Neonatal Expenses Fund (NEF) which was launched in Scotland on April 1<sup>st</sup> 2018, enabling parents of babies who need treatment</p>

in neonatal units to claim expenses to offset the cost of their travel and meals when visiting their children in hospital.

The evaluation of NEF attached Neonatal Expenses Fund year one: evaluation - gov.scot (www.gov.scot) which took place following the fund's first year of operation was considered. The evaluation noted that it was a valued offering by parents at a difficult time. The evaluation also set out the following recommendations: the need to consider a similar scheme for babies who move from neonatal to paediatric care; the importance of ease of applying; improving awareness of the Fund by families; and concerns around fraud risk.

The Child Health Commissioners for all 14 territorial Health Boards agreed that aligning a new fund with the NEF was preferable for consistency both for families and Health Boards.

YPFF was therefore designed to merge with NEF offering expanding to include support for families of child inpatients up to the age up to 18. Now if babies are transferred from neonatal care to a paediatric ward claims can continue to be made as long as other eligibility criteria is met. It also means that babies who are discharged but need a hospital stay are also covered.

The claim forms and wider documentation has been developed in ways which aim to strike an appropriate balance between ease of completion for the claimant and Health Board requirements regarding financial management and due diligence in respect of counter fraud measures. This will be kept under review to make sure the correct balance continues to be struck. Counter Fraud Services are also working with the Scottish Government and Health Boards to ensure that funds are directed at those who need them most, and inappropriate claiming minimised to protect the scheme and those using it being directed to avoid duplication of claiming.

Work to improve knowledge and uptake of YPFF will continue with marketing avenues explored in 2022.

Evidence also pointed to the need to accommodate families who may have additional children beyond any receiving inpatient care. In such cases the siblings may play a central role in offering emotional support to an inpatient and the parents may struggle to provide care to all children when frequent hospital visits are required. Data on household composition from the Scottish Household Survey was therefore considered and this showed that the majority of



	<p>households with children in Scotland have one or two children. The Fund will therefore cater for siblings up to the age of 18 for any eligible inpatient. This will help to ensure that parents or primary carers can more easily bring other children to hospital. This approach removes consideration of parents having to source and pay for childcare for children not visiting hospital and it helps to ensure that inpatients can see their brothers and sisters as well as their parents.</p> <p>A report on children in hospital from Ireland: <u>Report from Ireland</u> found that those on higher incomes were more likely to successfully access the non means-tested schemes. 51% found applying for state support was 'very difficult'. The YPFF is not means tested and accessing YPFF will be made as easy as possible. Uptake will also be monitored annually with a view to understanding and improving how families from all demographics access the fund.</p>
<p>Children and young people's views and experiences</p>	<p>A report from 2009 on children's and young people's experiences in hospital: <u>Children's and Young People's Experiences in Hospital</u> by <u>Maria E.B Edwards</u> from 2009 explores the experiences of 46 children and young people in hospital. The sample included children and young people of various ages, with some being admitted with an acute illness and some suffering from long term conditions. Theme 3 of the paper explores the role of parents and their care of children in hospital settings.</p> <p>Many children and young people believed that their parents cared for them the most whilst they were in hospital. (p.196)</p> <p>Children and young people described how their parents provided emotional support to them by "staying here with me", (...) "talking and keeping me company", "playing games" and "making it seem more normal".(p. 197) The presence of parents also provided some familiarity to children in an unfamiliar setting.</p> <p>Children and young people with chronic illnesses, whose parents usually provided complex aspects of care and treatment within the home setting, often preferred for their parents to continue to provide this care within the hospital setting. (p. 196)</p> <p>Children and young people associated the importance of their parents' participation in relation to the quality of care their parents were able to provide as part of their unique relationship with them (p. 199).</p>



	<p>Children also reflected on the importance of having parents around in light of pressure on staffing when nurses may be unable to attend to a child, leaving the child feel lonely (p 199)</p> <p>The study also addresses concerns many children and young people expressed for their parents due to their continued presence with them in hospital. Many appeared to relate to the situation their parents were in and showed concern for their welfare, highlighting concerns over them being tired, missing meals, being worried and not being able to spend time at home. (p 200).</p> <p>The Young Patients Family Fund will help to ensure that many of the views of children and young people can be acted on and supported. However, as the Young Patients Family Fund is a new fund (launched on 26 July 2021) there has been limited opportunity to gather the views of children and young people in respect of this fund in particular. The Scottish Government will therefore continue to find ways to include children and young people as relevant policy develops and the fund is further refined and embedded into health services.</p>
<p>Key Findings, including an assessment of the impact on children's rights, and how the measure will contribute to children's wellbeing</p>	<p>The assessment found that the costs of visiting a sick child could have a big impact on family finances and add to the emotional strain on families at a difficult time. It was clear that children and young people benefitted from having their family visiting and that it helped the family bond. The Young Patients Family Fund will enable parents, carers and/or siblings (aged under 18) to visit young hospital inpatients regularly and to provide vital support and be active partners in the child's health care (Articles 2, 3, 6, 12, 18(1,2,3), 23, 24 of the UNCRC). It will help to maintain emotional ties between the child and their parents, carers and/or siblings while they are undergoing treatment in hospital. It will reduce the financial burden for a family with a child in hospital (article 27 (1-3) of the UNCRC).</p>
<p>Monitoring and review</p>	<p>The application of the Fund will be reviewed after the first year.</p>
<p>CRWIA Declaration</p>	
<p>Authorisation</p>	
<p>Policy lead Fiona McKinlay, Policy Manager, Improving Health and Wellbeing</p>	<p>Date 18 May 2022</p>

Deputy Director or equivalent Mairi Macpherson, Deputy Director Improving Health and Wellbeing	Date 20 May 2022
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