

ResQ Family Study

Impact of **R**espiratory Syncytial Virus (RSV) Hospitalisation on **Q**uality of Life of **F**amilies – A Multi-Country Study

RESEARCH NEWS



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A HOLISTIC VIEW OF RSV: EVALUATING THE BURDEN OF A CHILD'S HOSPITALISATION ON PARENTS' HEALTH-RELATED QUALITY OF LIFE



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The Respiratory Syncytial Virus (RSV) is a common infection in children below 2 years of age. It can have an unpredictable disease course and may require sudden hospitalisation, especially in infected newborns. While the effects on the child itself have been the subject of several scientific studies, the overall burden on the family has not yet been fully investigated. Among others, parents' mental health is severely impacted by worrying about the sick child, adding on to the feeling of guilt for not being there for the siblings waiting at home. Moreover, parents often report feeling overwhelmed for not fulfilling their job responsibilities properly while the child is receiving extended treatment in hospital. To shed light on the overall burden on families with a child hospitalised due to RSV, EFCNI initiated the ResQ Family project.

138 parents from four European countries participated in the study. Their responses highlight the drastic impact of the child's health status on parents' health-related quality of life and family functioning and reveal potential stressors that must be addressed in the future to minimise the negative impact on affected children and their families.

The highly contagious Respiratory Syncytial Virus (RSV) causes acute lower respiratory tract infections with an unpredictable course of the disease, especially in newborns and infants. While an RSV infection shares many symptoms with a common cold, infected children often show more severe breathing difficulties and wheezing. In addition, the unpredictability of the disease can lead to an unforeseen severe course, resulting in a sudden and severe progression, potentially necessitating hospitalisation. This can profoundly disrupt and challenge the family's daily life.



Understanding how a hospitalisation due to RSV impacts families

To better understand the true burden on affected families, the ResQ Family project was initiated. Researchers from EFCNI developed a comprehensive questionnaire with the support of a diverse panel of external experts to elaborate on the parental health-related quality of life along with associated dimensions. A total of 138 parents from France (n = 60), Germany (n = 32), Italy (n = 28), and Sweden (n = 18) participated and were also invited to take part in a follow-up survey 6 weeks later.

Parents struggle with additional challenges in both their personal and professional lives

Among the study population, children with RSV had to be **hospitalised for an average of 6 days** where **almost all RSV-infected children (94%) had to be monitored** for heart rate and respiration. While **80% required additional oxygen**, some even had to undergo invasive respiratory support such as intubation or mechanical ventilation, as displayed in the figure below.

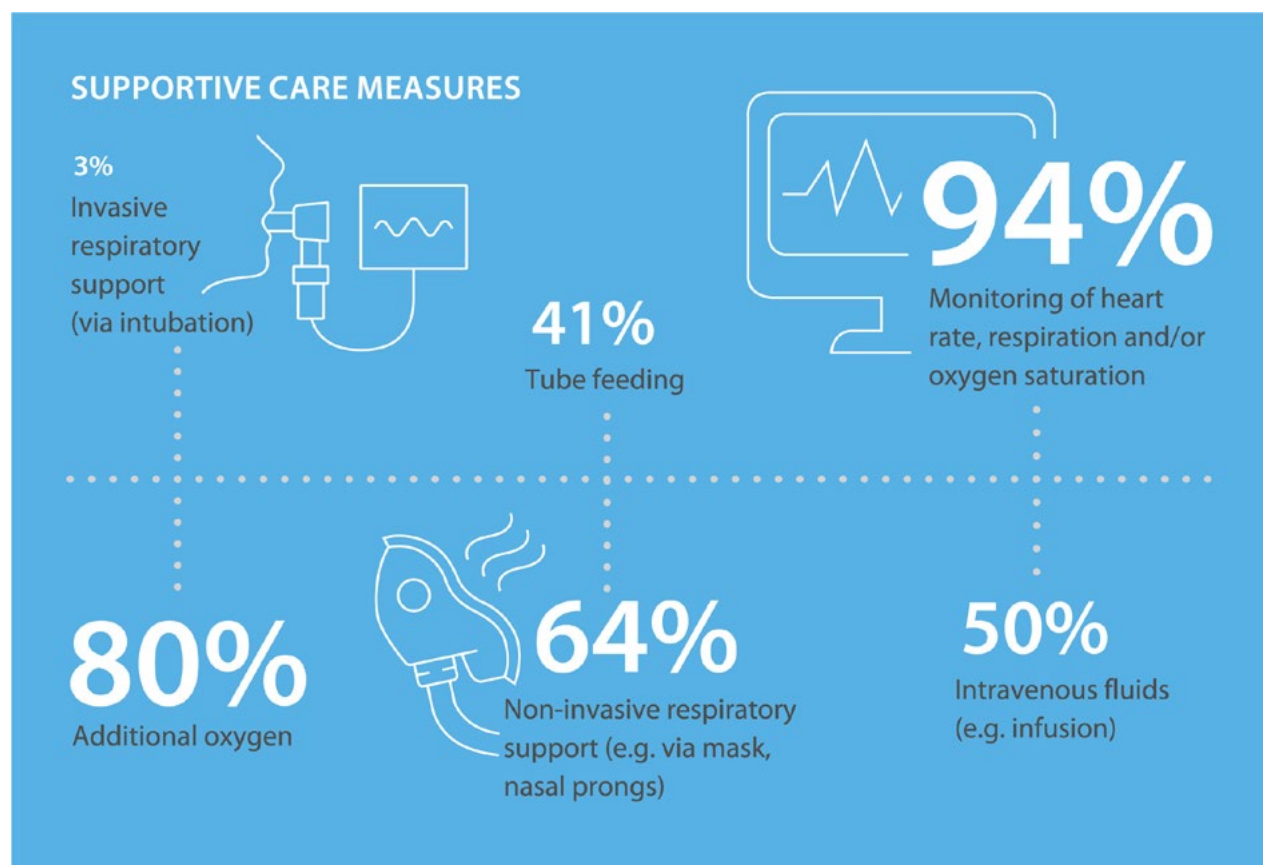


Figure 1: Supportive care measures required during hospitalisation

During this time, parents and caregivers found themselves in a difficult situation where they had to divide their attention between the sick child in hospital and the rest of the family while still maintaining their everyday lives. **More than 90% of parents struggled** with worrying about their child's health in addition to feelings of stress, guilt, and loneliness.



When a child has to be hospitalised due to a severe RSV infection, the entire family is affected. Alongside the conflicts in their private lives, parents also experienced negative effects in their professional lives. 40% of parents who were working during the period of hospitalisation suffered a great loss of work productivity and missed an average of 29 working hours.

Figure 2 visualises further barriers parents encountered when seeing their hospitalised child. **The long distance** to the clinic, associated **costs**, and increased **organisational efforts** augmented stress and worry for up to one third of caregivers.

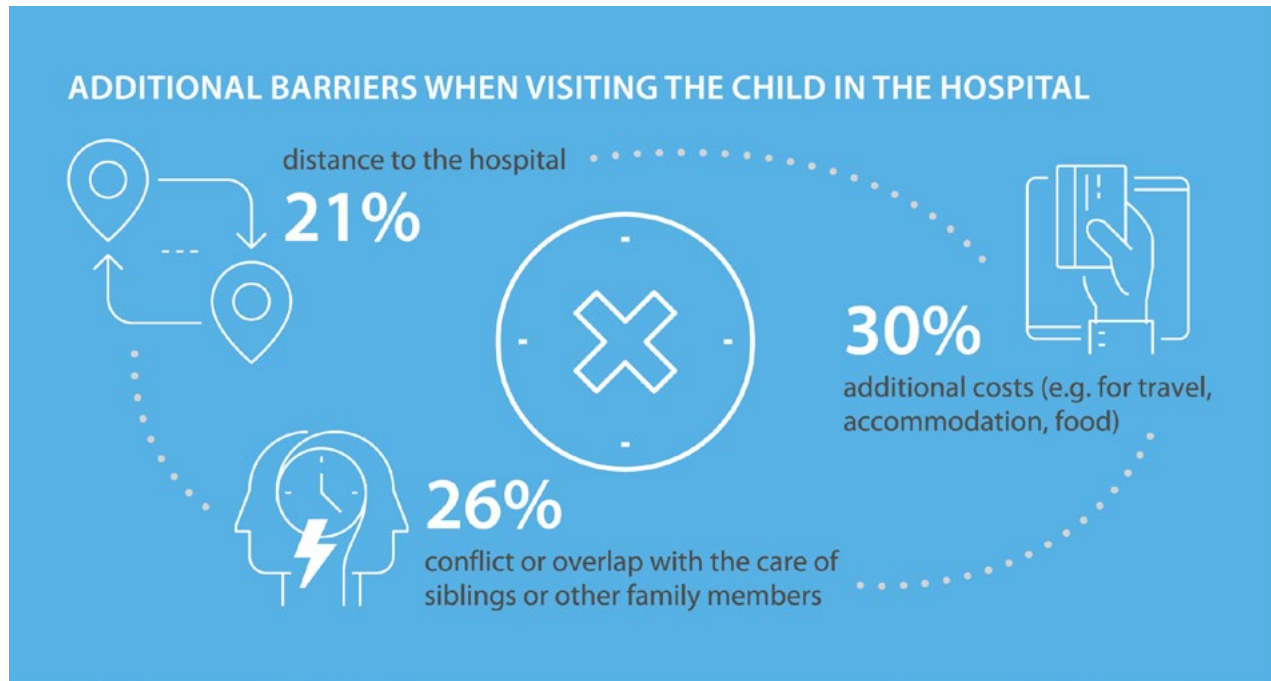


Figure 2: Additional barriers for parents/caregivers when visiting the child in hospital

All these factors may have the potential to interact as stressors, collectively affecting the general health of those impacted. The study revealed that parents' health-related quality of life was significantly diminished by the RSV-related hospitalisation of their children, with "daily activities" being the most affected aspect of family life across all countries. While there was a slight improvement at the follow-up examination, the parents' quality of life remained impacted. This is particularly concerning because **parents continued to experience emotional burdens** weeks later, which can, in turn, affect the care of the children and the overall functioning of the family in the long term.

The challenges parents face may differ from country to country

The ResQ Family findings highlight that parents in different countries are differently affected by their child's hospitalisation. While Italian and German parents had significantly more problems organising the care of other family members, French and Italian parents were more affected by feelings of loneliness and guilt. This is especially alarming given the fact that **more than 70% of parents did not receive adequate information on mental health support**. Compared to German and Italian hospitals, Sweden and France offered a better support network for affected families which in turn could have counteracted the negative impact on quality of life dimensions.

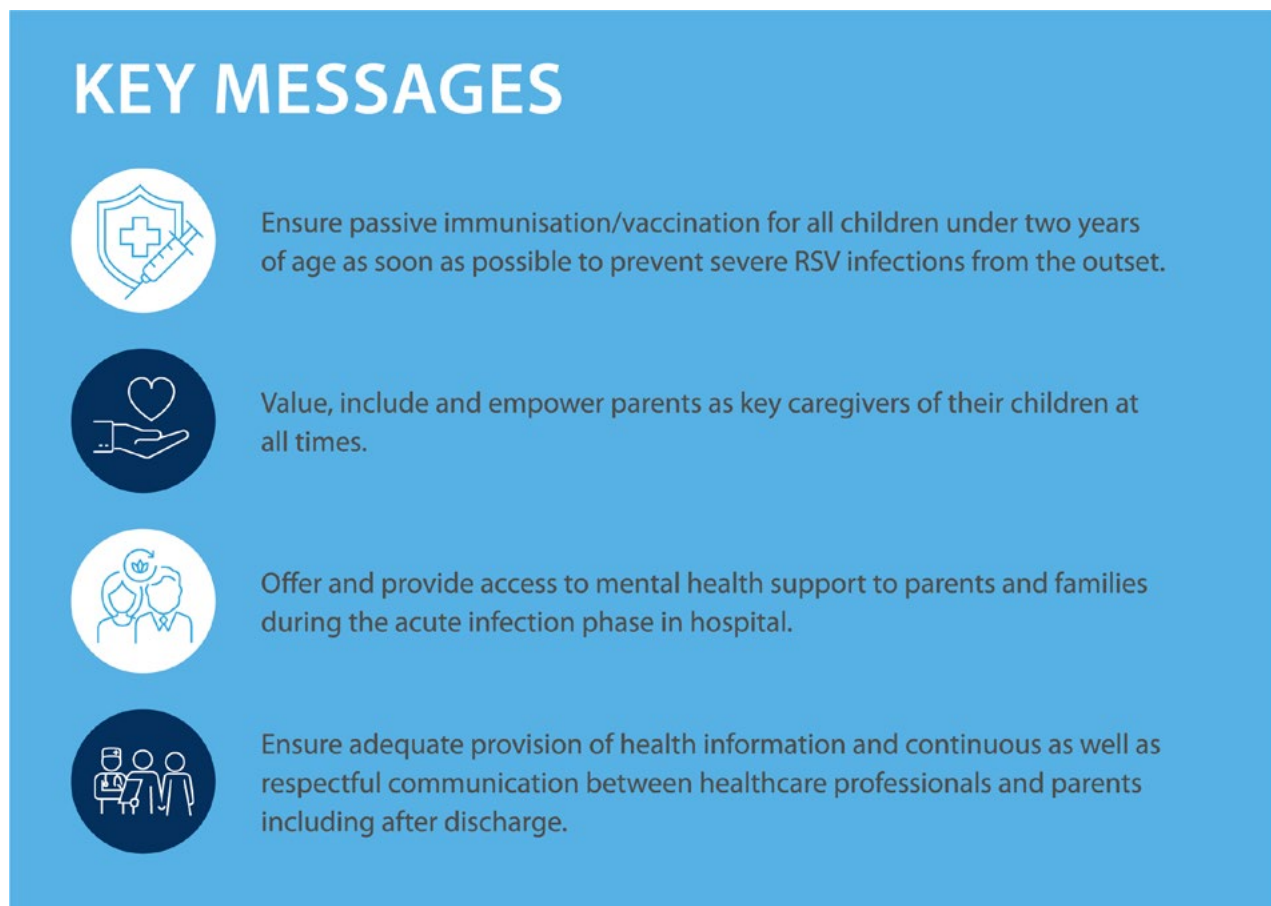


In general, given the significant reduction in parents' health-related quality of life, it is striking that nearly half of the participants (44 to 54%) underestimated the substantial impact the virus would have on their personal and professional lives. This highlights the study's importance in revealing RSV's far-reaching effects on the entire family and underscores the need to enhance parents' awareness about the disease consequences and the prevention options.

Suitable intervention and prevention measures needed

The ResQ Family study also identified potential protective measures that might reduce the burden on parents. Healthcare professionals can help to improve support services for parents, including mental health support and reduced stress through a constant maintenance of family involvement, improved relationships in the hospital and expanding the offer for mental health support.

The study concludes that children and their families may be protected best from the consequences of an RSV infection if suitable interventions and prevention measures at societal, educational, and policy levels work together to effectively reduce the global burden of RSV. Further efforts are needed to engage all educational backgrounds and parental groups to ensure comprehensive awareness and enhance parental health literacy to guarantee every newborn the best possible start into life. In detail, the following core statements displayed in figure 3 are proposed, aimed at all key interest groups:



The graphic is a blue rectangular box with the title 'KEY MESSAGES' in white, bold, uppercase letters at the top left. Below the title are four rows, each featuring a circular icon on the left and a text block on the right. The icons are: 1) A white shield with a cross and a syringe on a blue background. 2) A white heart held in a hand on a dark blue background. 3) A white icon of two people with a heart above them on a white background. 4) A white icon of a person in a hospital bed with another person standing by the side on a dark blue background.

KEY MESSAGES





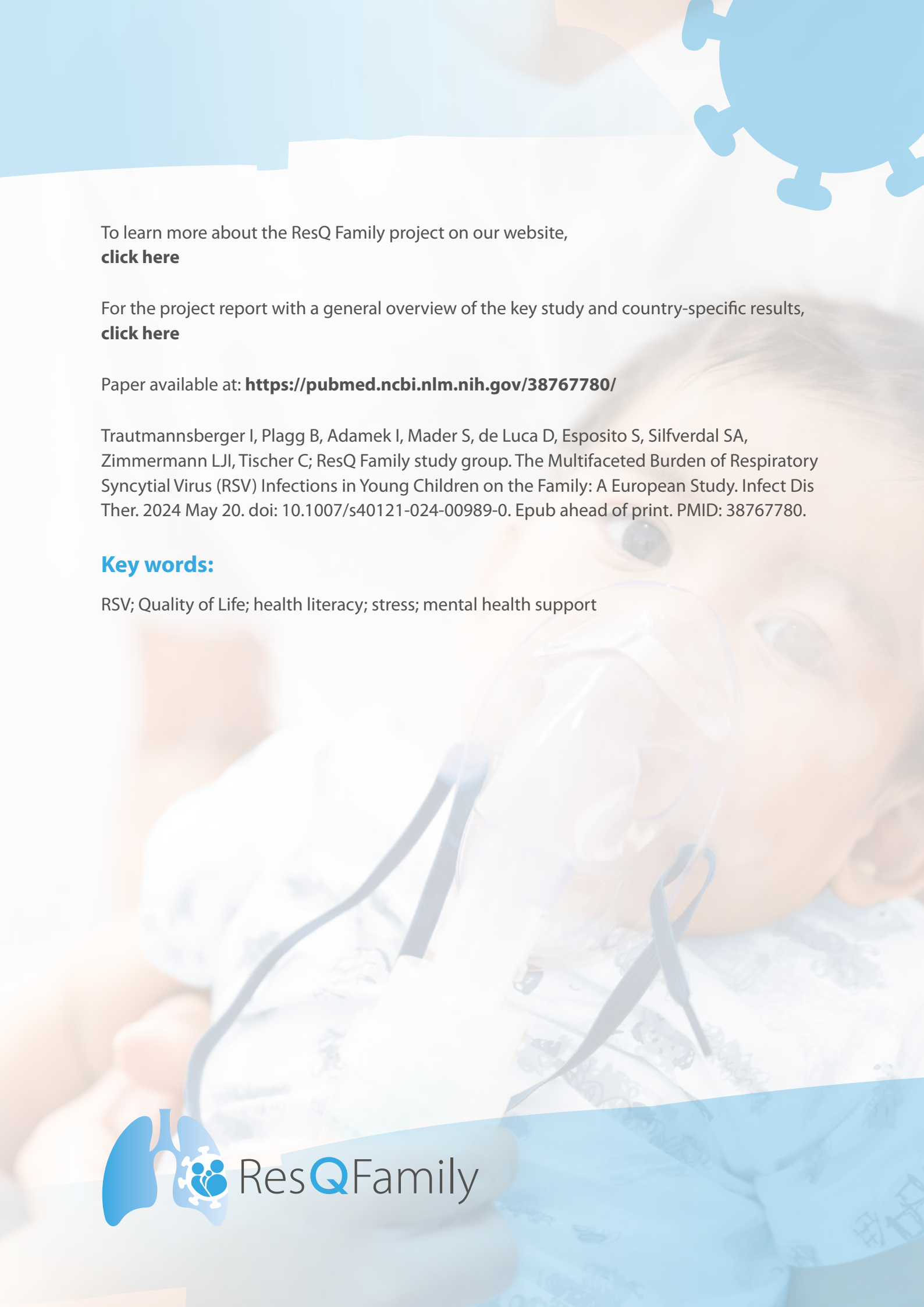
-  Ensure passive immunisation/vaccination for all children under two years of age as soon as possible to prevent severe RSV infections from the outset.
-  Value, include and empower parents as key caregivers of their children at all times.
-  Offer and provide access to mental health support to parents and families during the acute infection phase in hospital.
-  Ensure adequate provision of health information and continuous as well as respectful communication between healthcare professionals and parents including after discharge.

Figure 3: Key messages for stakeholders and decision-makers





To learn more about the ResQ Family project on our website,
click here

For the project report with a general overview of the key study and country-specific results,
click here

Paper available at: <https://pubmed.ncbi.nlm.nih.gov/38767780/>

Trautmannsberger I, Plagg B, Adamek I, Mader S, de Luca D, Esposito S, Silfverdal SA, Zimmermann LJ, Tischer C; ResQ Family study group. The Multifaceted Burden of Respiratory Syncytial Virus (RSV) Infections in Young Children on the Family: A European Study. *Infect Dis Ther.* 2024 May 20. doi: 10.1007/s40121-024-00989-0. Epub ahead of print. PMID: 38767780.

Key words:

RSV; Quality of Life; health literacy; stress; mental health support