



Neonatal Expenses Fund: a process evaluation of the first year of implementation



CHILDREN, EDUCATION AND SKILLS

Executive Summary

Background

This report presents the findings of a process evaluation of the Neonatal Expenses Fund (NEF) during its first year of implementation. The NEF was launched in Scotland on April 1st 2018, enabling parents of babies who need treatment in neonatal units to claim expenses to offset the cost of their travel and meals when visiting their children in hospital. The evaluation aimed to examine the uptake of the NEF over its first year of implementation, to evaluate the process of claiming from the fund, and seek parents' views on the value of being able to make NEF claims.

Method

The evaluation findings are based on two web-based surveys conducted by the Scottish Government during June and July 2019 and financial data on NEF spending provided by each of the 14 health boards. The first survey asked parents whose children had been treated in neonatal units between April 2018 and March 2019 about their experiences of the NEF. This survey was advertised to parents via Bliss, a charity which supports families of sick and premature babies. It is important to note that the survey respondents were not a representative sample of the whole population of parents with children in neonatal care, meaning that findings must be interpreted with caution and cannot be generalised to all parents in this situation. However, they highlight some of the strengths and weaknesses of the fund and illustrate how the fund is being experienced through Scotland.

The second survey asked hospital staff working in neonatal units and finance offices about their experiences of the implementation of the fund. This was sent to each neonatal unit for staff to complete.

Main Findings

Overall, parent respondents who used the NEF gave positive feedback. The majority agreed that using the fund relieved financial anxieties during a very stressful period, and helped them to visit their children in hospital frequently.

A small number of parents had not been aware of the fund but felt that they would have benefited from it if they had known they could claim. And a small number of parents chose not to claim despite being aware of the fund, and did not think that this affected their ability to visit their child in hospital.

A number of areas for improving the implementation of the NEF were raised. These related to the advertising of the fund, the clarity of information about the fund and how to use it, and the process of making and receiving a claim.

1. Introduction

Background

This report presents the findings of a process evaluation of the Neonatal Expenses Fund (NEF) during its first year of implementation. The NEF was launched in Scotland on April 1st 2018, with £1.5 million committed to the fund over the first twelve months.

In 2017 *The Best Start: A Five Year Plan for Maternity and Neonatal Care in Scotland* recommended that a review of the approach to family expenses be carried out to reduce variation across Scotland. Bliss, the neonatal charity in its 2014 report *'It's not a game: the very real costs of having a premature or sick baby - Scotland'¹* estimated the additional cost in Scotland for parents of babies in neonatal care is £218 a week (of £282 for UK), and an average extra total cost of £2,045 (£2,256 for UK) over their baby's entire stay in hospital. This was based on a 2013 survey that received 1300 responses in total of which 85 were from Scottish parents. The costs incurred include items such as food, accommodation, parking charges, and costs of childcare for older siblings.

The Neonatal Expenses Fund (NEF) was launched on 1st April 2018 and is designed to help parents of premature and sick new born babies who require neonatal care to offset their costs of travelling to and from hospital and subsistence during first days, weeks and months of their babies' lives. All parents whose children have been admitted to a neonatal intensive care unit, a local neonatal unit or a special care baby unit are entitled to claim expenses from the NEF. These expenses are intended to offset the cost of travel to visit their baby in hospital and the cost of eating their meals at the neonatal unit.

Parents/guardians can claim for travel and parking, as well as a food allowance of up to £8.50 per day for meals eaten while visiting their baby. Parents/guardians can choose whether to make multiple claims during their baby's stay in the neonatal unit, or to claim for their entire stay when their baby is discharged from hospital.

The NEF is distributed by all 14 territorial NHS health boards, with parents being reimbursed by the health board in which they reside for their expenses.

Aims and Objectives

This process evaluation aimed to examine the uptake of the NEF over its first year of implementation and to evaluate the process of claiming from the fund.

The specific objectives were:

- To describe the uptake of the NEF during its first year across Scotland;
- To understand parents' perceptions of the value of the NEF and its effect on their lives;

¹ <https://s3.eu-west-2.amazonaws.com/files.bliss.org.uk/images/Bliss-not-a-game-Scotland.pdf?mtime=20180409142925>

- To understand parents' reasons for choosing whether or not to claim from the NEF, to understand any barriers to take-up, and to make recommendations on how take-up can be improved;
- To evaluate the NEF's implementation processes and make recommendations on how these can be improved.

2. Method

2. a. Research Method

There were three aspects to this research: the collection of financial and neonatal admissions data; a parent survey; and a staff survey.

Financial Data

Data was requested from each of the 14 health boards to report on NEF spending.

Parent Survey

Data from parents was collected via an online survey of parents whose children had received treatment in any neonatal unit in Scotland between the period 1st April 2018 to 31st March 2019. Parents were recruited via online promotion of the survey by Bliss, a third sector organisation supporting premature and sick babies and their families. Parents were not recruited via the NHS or through the use of health data. The survey was open for a period of two months in June and July 2019.

Staff Survey

Data was collected via a second online survey from finance staff from all 14 health boards and neonatal ward staff in all 16 neonatal units in Scotland. Staff were recruited via email invitations sent to all neonatal units in Scotland. This survey comprised of a mixture of open and closed questions about the process of implementing the NEF and was open for a period of approximately six weeks in June and July 2019.

Ethical considerations

Participation in both surveys was voluntary and all survey respondents were provided with an online consent form and privacy notice on commencing the survey. All necessary steps were taken to ensure that all data collection complied with GDPR and to ensure the anonymity of respondents. All quotes used in the final report are anonymous, and any potentially identifiable data has been redacted.

2. b. Sample Profile

Parent Survey

In total, 152 parents completed the survey. Of these respondents, 53 were excluded from the analysis because they stated that their child was not being treated in a Scottish neonatal unit during the 12 month evaluation period. The analysis of the parent survey is therefore based on the remaining 99 respondents whose children were admitted to neonatal units within the evaluation period (see Table 1). 68% of these respondents had made a claim to the NEF. Of those who did not make a claim, 19% stated that they had not been aware of the NEF, while 11% had been aware of it but chose not to claim.

Table 1: Respondents by claiming status

NEF claiming status	Number of respondents
Made a claim for expenses under NEF	67
Did not make a claim for expenses but were aware of the NEF	11
Did not make a claim for expenses and were not aware of the NEF	19
Did not state claiming status	2
Total	99

Of the 99 parents eligible to take part in the survey, 94% identified as either White British or White Scottish and 4% identified as White Irish. The most common age group was 30-34 (40%), followed by 35-39 (27%). No parents under the age of 20 or over the age of 44 took part in the survey. Respondents were spread across all five SIMD quintiles, with SIMD 3 the most common (26%). Taken together, slightly more parents from SIMD 4 and 5 responded than parents from SIMD 1 and 2. Demographic information about all the families whose children were admitted to neonatal units in Scotland during the evaluation period is not available. Variation may exist between these parents and parents who responded to the survey. Given this, it is not possible to definitively state that the responses from the parent survey are relevant to the whole population of parents of children admitted to neonatal units in Scotland.

For the majority of respondents, their children had stayed in a neonatal unit for between 6 weeks and 6 months (46%). Only 8% had children who had stayed for less than one week, and 2% had stayed for more than 6 months. The majority of parents who responded had babies who were admitted to the neonatal unit after the NEF scheme had been rolled out (90%), with the most common periods of admission being July-September 2018 (31%) and January-March 2019 (29%). Parents were asked which neonatal unit their child was first admitted to, 13 of the 16 neonatal units in Scotland indicated by parents.²

Staff Survey

The staff survey was completed by 101 respondents. 81 respondents identified themselves as neonatal ward staff, 15 as finance staff, and 15 as “other” staff.

Responses from neonatal ward staff were received from 12 out of the 16 neonatal units in Scotland.

² See appendix.

2. c. Limitations

It is important to note that the samples of parents and staff used in this study are self-selected samples of respondents. As such, they are not representative samples of all parents whose children were admitted to neonatal units during the first 12 months of the NEF, or staff working in neonatal units during the same period. Limited time and resources meant that it was not possible to procure a representative sample in the time available to conduct this evaluation. As a result, the survey findings must be interpreted with caution and should not be taken as generalisable to wider populations. However, they highlight some of the strengths and weaknesses of the fund and how the fund is being experienced through Scotland.

3. Findings

3. a. Spending on the Neonatal Expenses Fund

In total, £235,220.70 was spent on the Neonatal Expenses Fund across Scotland between 1st April 2018 and 31st March 2019.

Table 2: Spending on the Neonatal Expenses Fund

NEF Spending	First 4 months	Full 12 months
Meals	£24,887.76	£99,107.01
Mileage	£21,241.06	£83,595.10
Public Transport	£7,837.57	£30,197.81
Parking	£3,070.02	£15,627.03
Taxis	£745.80	£3,532.84
Flights	£2,142.40	£3160.91
Total NEF Spending	£59,924.61	£235,220.70
Average Monthly NEF Spending	£14,981.15	£19,601.73

As Table 2 demonstrates, the largest proportions of spending were on meals and mileage, followed by public transport and parking. A smaller amount was spent on taxis and on flights for parents travelling to neonatal units from more remote areas.

The average monthly spending was £4620.58 higher averaged over 12 months than the average monthly spend during the first four months. This increase in average monthly expenditure is likely to be explained by increased knowledge of the fund among staff and parents as the year progressed. Some parents make a single claim for the whole stay following their baby's hospital discharge which may have also increased the average monthly spend.

3. b. Need

As Figure 1 shows a significant majority (92%) of parents who made NEF claims claimed for food and drinks bought in or around the neonatal unit. Most parents also made claims for transport, with mileage and parking being the most common types of travel claims, followed by public transport.

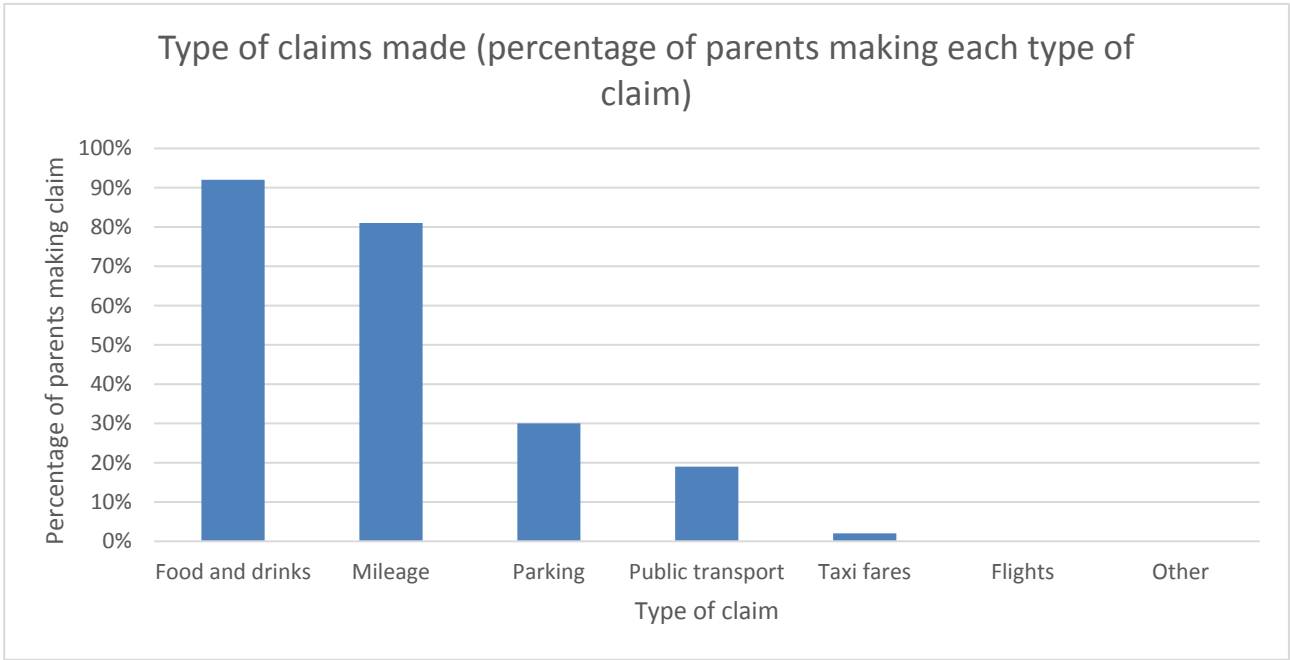


Figure 1: Type of claims made

Parent’s perception of the fund

As Figure 2 shows, among parents who made NEF claims, it was widely felt (94%) that being able to claim expenses reduced parents’ anxieties about money during the time that their babies were in neonatal units. Moreover, 72% felt that they were able to spend more time with their babies in the neonatal unit as a result of being able to claim expenses.

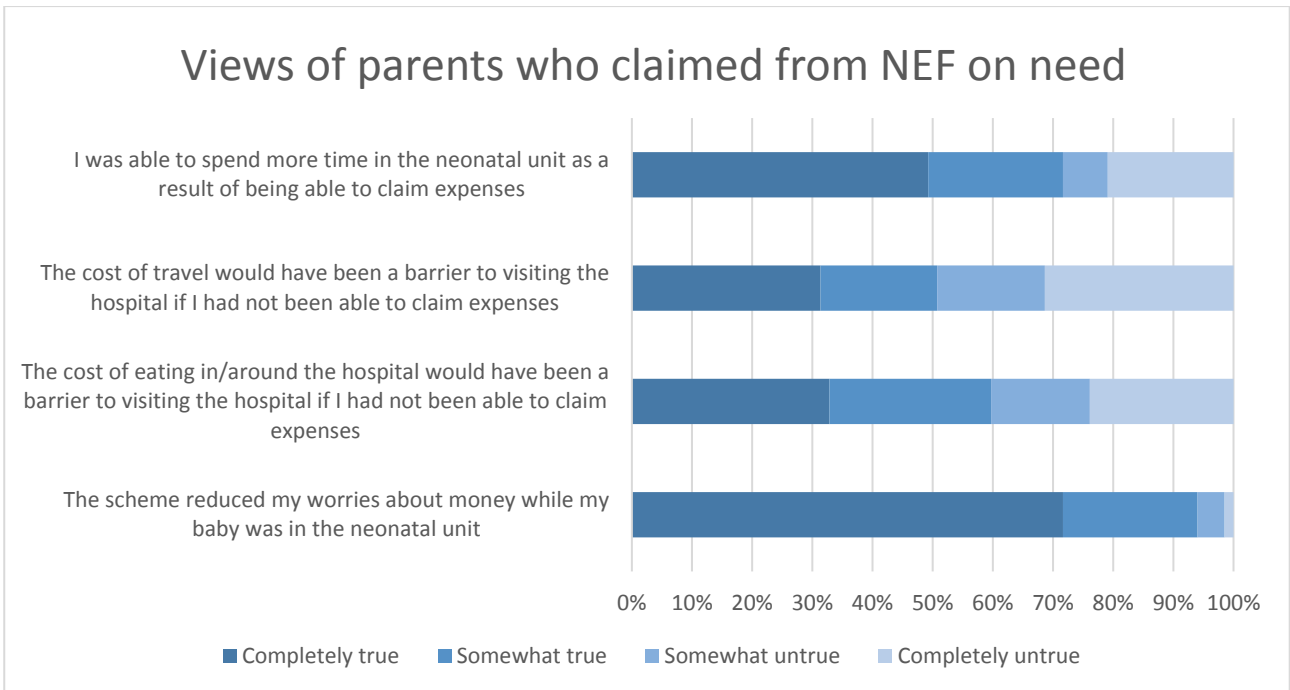


Figure 2: Views of parents who claimed from NEF

Parents commented on the importance of the fund:

"It was a weight off our minds when our daughter was critically ill and it allowed us to concentrate on being with her"

"The scheme is excellent. I would have paid anything to be able to be with my baby but knowing I could claim some of it back took a lot of stress off me during the most difficult time of my life"

A significant minority (39%) of parents who did not claim (as they were not aware of the NEF) felt that the cost of travel to and from the neonatal unit was a barrier to visiting the hospital as often as they wanted. Of those parents who made a claim, 51% felt if they had not been able to claim expenses that this would have been a barrier to visiting the neonatal unit. Parents who made claims commented on the importance of the fund in enabling them to travel to the hospital:

"Luckily I got to stay at [the] hospital for the 9 weeks my daughter was there. But as for my husband, he had to use buses and spend 2-3 hours one way to come see us during the week. He would make 2-3 trips a week alongside him working. The buses aren't cheap. So we are so thankful we were allowed to claim his travel expenses back. Our daughter was born 12 weeks early and as I had to go off on maternity earlier, travelling back and forth would make us struggle financially if it wasn't for the expenses."

"The scheme makes a huge difference to my family and means that we can spend time with my daughter without the concerns of how we are going to manage the cost of travelling to the [neonatal unit] especially when there is a prolonged stay."

The cost of eating in and around the hospital was also perceived as a barrier to spending time in the neonatal unit by 50% of parents who were not aware of the NEF. Similarly, 60% of parents who made a claim felt that this would have been a barrier to visiting the hospital if they had not been able to claim expenses. One parent commented being able to claim from the fund for meals and the importance this had on their health:

"I means that I eat proper meals and this helps maintain my milk supply, allowing me to continue to produce breastmilk for my daughter. This is vitally important for her health and development. Without the neonatal fund this stressful experience would have been even more stressful and far more difficult to negotiate."

The one issue raised by parents relating to need was that parents became ineligible to claim from the NEF if their child needed to stay in hospital but was moved out of the neonatal unit. As one parent commented:

"My son was in neo-natal for 10 days before moving to a cardiac ward. His condition hadn't changed and [he] was still high dependency-nursed but the expense stopped. We were still in exactly the same situation as we were in neo-natal, just unable to claim. My son as so far spent 10 weeks

in hospital and we've struggled financially in terms of petrol [for] coming up and down to hospital. There's no financial support other than one off donations from charities to help parents with babies not in neo-natal but in long term hospital. The fund, even if it was just rolled out to cover fuel/travel, would help enormously"

The responses from parents who claimed or who would have claimed if they were aware of the NEF demonstrate the importance of the NEF in reducing financial stress, removing barriers to visiting their baby in hospital, and maintaining maternal health.

Of the Parents surveyed, 11% knew about the NEF but chose not to claim. Being able to afford to visit the hospital without making a claim was the most common main reason given for not claiming (50%). None of these parents felt that they had missed out on spending time with their child/ren in the neonatal unit as a result of not making a NEF claim.

However, given that parents from wealthier SIMD categories appear to be over-represented in the parent survey, it is likely that these survey results under-emphasise the importance of the NEF for reducing anxieties about money and removing barriers to parents spending time with their babies in the hospital.

Around 20% of respondents (n=19) indicated that they did not make a claim because they were not aware of the NEF. Of those parents who knew about the NEF and did not claim, 20% chose not to claim because it seemed too complicated and/or time-consuming. They were asked to indicate any changes that would encourage them to claim if they were eligible again in the future. The four most common responses were:

- 55% of parents suggested that they would be encouraged by “clearer information from the beginning about the need to keep all receipts”;
- 55% suggested they needed “more information about the fund”;
- 46% suggested a “simpler claims form”;
- 46% suggested “not having to show receipts”.

These responses indicate that a lack of clear information about the NEF, as well as some aspects of the process of making claims, were barriers to parents making NEF claims.

3. c. Advertising and information about the fund

The majority (79%) of parents who made NEF claims said they first heard about the scheme from neonatal ward staff. The second most common way that parents first found out about the fund was via posters on the ward (12%). Small numbers of parents first found out about the fund via friends/family, other parents in the unit, and Bliss staff. The majority of parents who did not make a claim and did not know about the NEF said that they would have made a claim if they had known about it. This suggests a need for better communication of the NEF to ensure that all parents are aware of the fund. This will be discussed in more depth later in the report.

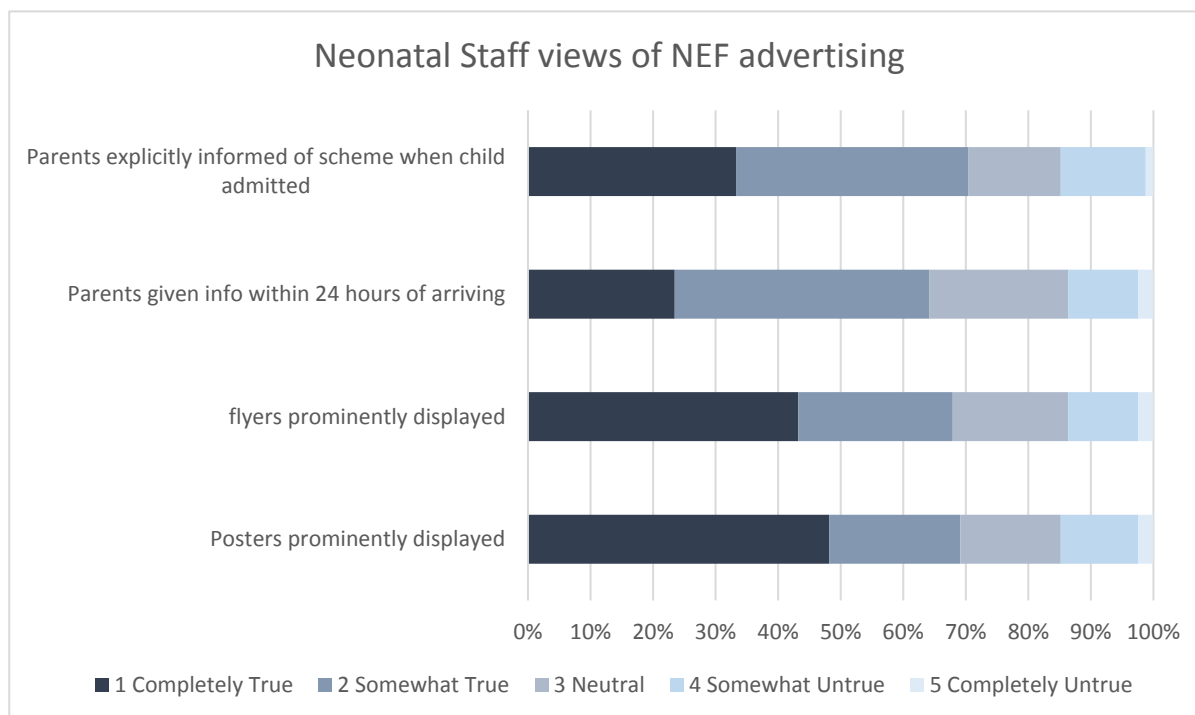


Figure 3: Neonatal staff views of NEF advertising

As figure 3 shows, responses from neonatal ward staff suggest that while the majority of neonatal wards explicitly informed parents of the scheme and displayed posters and flyers prominently, this was not consistent across neonatal units. Staff highlighted several concerns relating to the lack of awareness of the NEF among parents. Some noted that parents were often either not told about the fund immediately, or were too worried about their child to be able to process the information that they received about the NEF in the first few days of their baby's admission to the unit. This lack of awareness meant that some parents were not able to make claims either because they didn't know about the fund, they did not realise early enough that they needed to keep their receipts or they did not have enough information to make the fund accessible.

Staff also noted that some parents assumed that they were ineligible because of the wording of the poster advertising the scheme. The poster asked "Neonatal Expenses: Are you eligible?", which staff felt gave many parents the impression

that the NEF is means-tested and that they would not be eligible if they did not receive benefits. As one parent also commented:

“We had seen posters but just assumed, because we both worked full time and didn't claim benefits, we wouldn't be entitled, despite the fact it [having a baby in a neonatal unit] was still causing us financial difficulty.”

The majority of neonatal ward staff indicated that the information provided about the NEF to parents was clear, with 69% feeling that the overall process of making NEF claims was clear to parents.

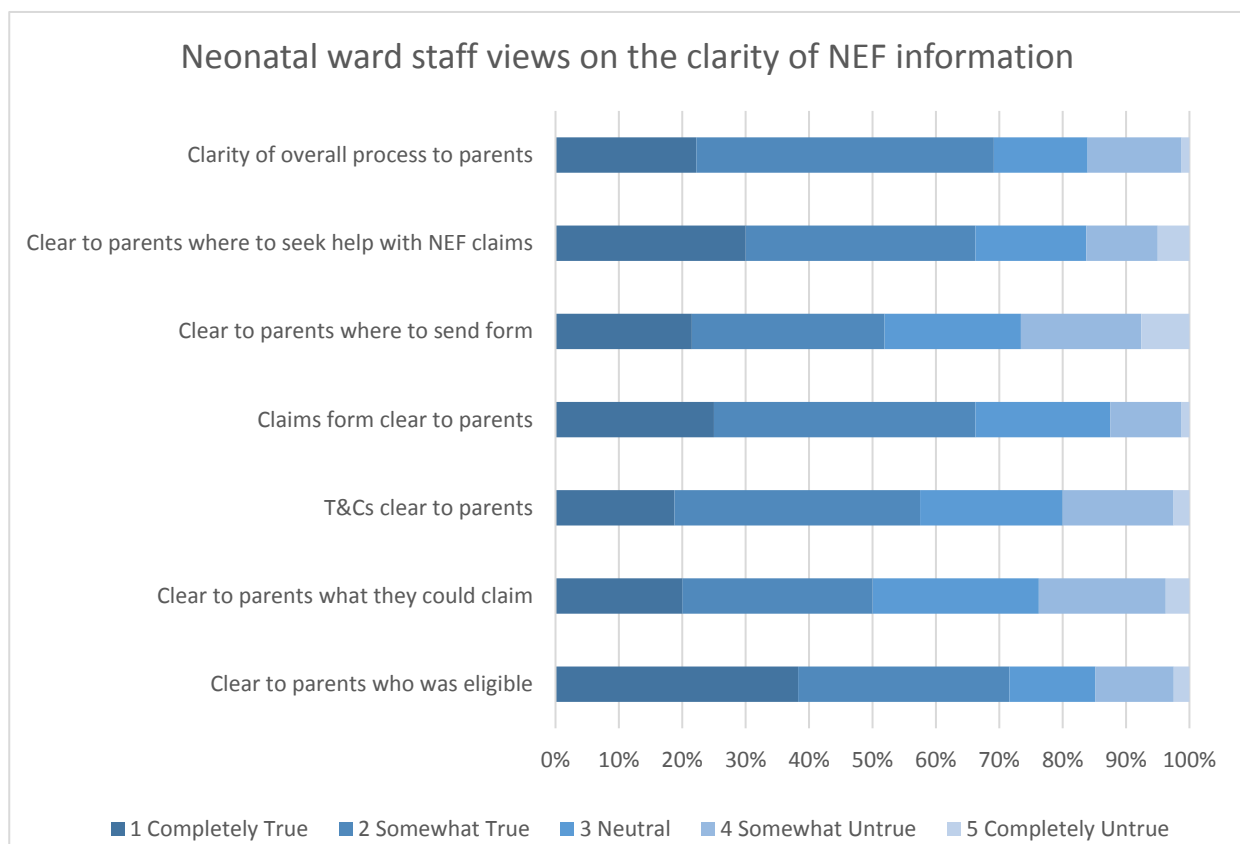


Figure 4: Neonatal ward staff views on the clarity of NEF information

The information about where parents should send their claims forms and what they were allowed to claim were seen by staff as being the least clear, with 26% and 23% of neonatal staff respectively stating that these were not clear to parents. Furthermore, 20% noted that the terms and conditions of the NEF were not clear to parents.

Similarly, 27% of staff noted that it was not clear to them where parents should send their claim forms, 27% stated that it was not clear to them what food parents could and could not claim for, and 19% said that it was not clear to them what travel expenses parents could and could not claim for.

The most common cause for concern about claims raised to staff by parents focused on the difficulties faced by parents whose children were admitted to neonatal units outside the NHS board area in which the family resides (23%). Responses from staff and parents suggest that there was a perceived lack of clarity about where to send claim forms. It was not clear that parents who were attending a neonatal unit in a health board area that was different to the one that they live in needed to claim expenses from their “home” health board area. As one staff member commented:

“there is still confusion as to where parents go to claim, when they are being cared for in another hospital but need to go back to [their] base hospital to claim, which could be 50 miles away or more”.

This was seen by both staff and parents to be impractical and causing an extra source of anxiety to an already stressful time for parents. As one parent commented:

“[The] finance office in the hospital where my baby was refused to accept the claim. They sent me to a hospital closer to my home who did not have a neonatal unit [and which was] not experienced in this claim form. They asked me if I could go to another hospital further away (which I refused). Being sent to another hospital was not acceptable. It was a major barrier to claiming. The simplest solution would be for parents to claim at the hospital where their baby is or an online claim form.”

Several issues were raised by parents and staff in relation to the lack of clarity about what expenses parents were allowed to claim. The main issues raised were: that it was unclear whether they could buy food outside of the hospital; what types of food could be reimbursed (e.g. whether the food bought needed to be a specific meal); whether taxi journeys could be included as travel expenses; and whether one or both parents were allowed to claim public transport and meals expenses on the same day.

The comments submitted by both parents and staff suggest that there is inconsistency across different hospitals in how the terms and conditions relating to these areas have been applied. For example, while some parents commented that they could only claim for one parent per day, for others this was not the case. Similarly, some health board areas allowed for the purchasing of food outside hospital grounds while others did not.

One parent suggested that the need for clearer information could easily be dealt with by providing more comprehensive written information on the fund when people arrive at the unit:

“If you were given a pamphlet or a booklet when entering neonatal it would be easier to come across the information.”

Parent and staff views on the process of making NEF claims

Among the parents who made NEF claims, it was widely felt that the process of making a claim was straightforward, with 93% of parents agreeing that “the scheme was easy to use” and reporting that they received their expenses payment quickly.

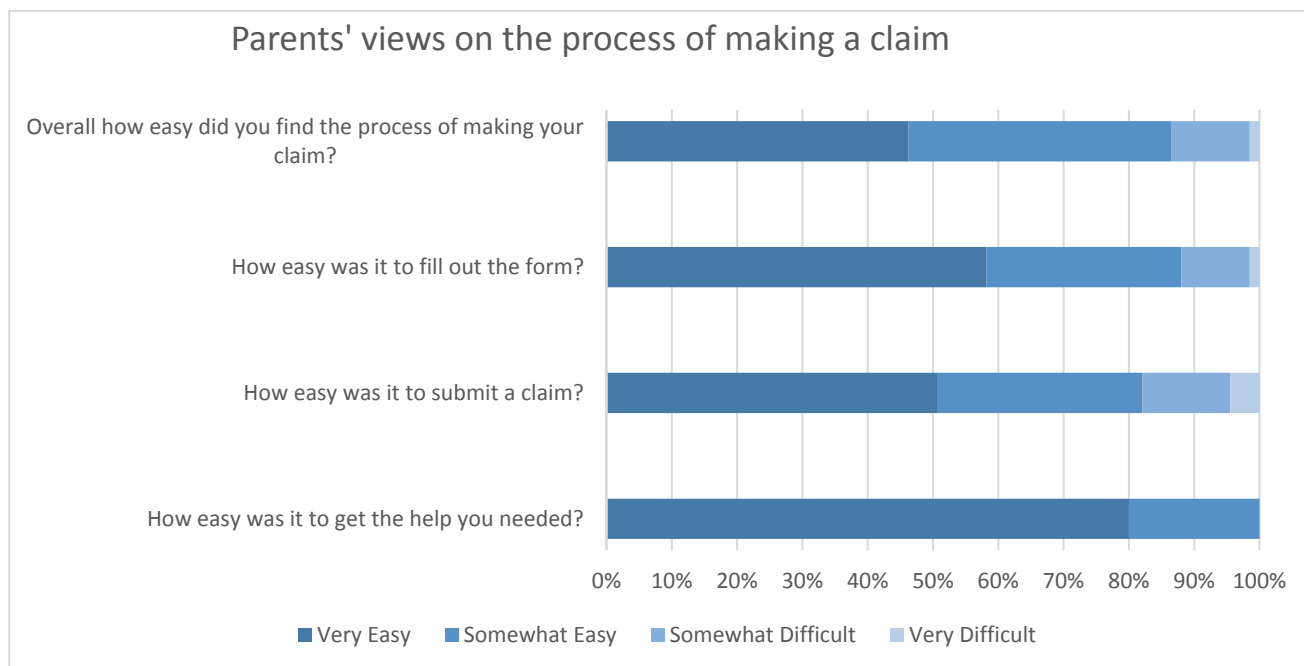


Figure 5: Parents' views on the process of making a claim

As figure 5 shows, 87% said that the overall process of making a claim was easy with a similar proportion reporting that the claim form was easy to complete, and 82% said that it was easy to submit their claim.

Compared with parents, a lower proportion of staff (68%) said that the claims form was easy to fill in, which is likely to reflect the fact that staff were interacting with a more diverse range of parents than the sample of parents used in this study.

Of the 67 parents who made a claim, 47 answered the question “did you encounter any challenges to making a claim”? Approximately a third of these (34%) said that they did encounter challenges. In total, 20 parents reported that they needed help with making their claim. Of this, 100 % found that it was easy to get the help that they needed.

Among those who encountered challenges, 44% indicated that they had issues because they did not have some or all of their receipts. Staff also indicated that this was a common concern, noting that some parents struggled to remember to keep their receipts while coping with the stress of their baby’s illness, while others did not learn of the fund immediately, so did not know to keep their receipts.

Of parents who stated that they encountered challenges, 38% said that they had “problems receiving payment”. Parents commented that the problems receiving payment included:

- A failure to be reimbursed for claims they had submitted;
- Parents being queried by cashier staff about claims that they had made;
- Some finance offices not always having enough cash available to reimburse parents immediately;
- Some finance offices only being able to offer reimbursement in the form of a bank transfer or cheque, when parents would have preferred cash;
- Parents having to spend too long at the cashier’s office waiting for their claims to be checked, approved and reimbursed, taking valuable time away from being with their babies.

4. Conclusions and Recommendations

4. a. Conclusions

This evaluation has examined the spending on the NEF during its first year of operation, the process of administering the NEF, and parents' views on their experiences of using the fund. As noted in the method section, however, it is important to note that the sample of parents surveyed is not representative of the wider population, and therefore the findings from the parent survey contained in this report cannot be generalised to the wider population.

Spending

In total, £235,220.70 was spent on the Neonatal Expenses Fund across Scotland during the 12 month evaluation period. The largest proportions were spent on meals and mileage. The average monthly spending was £4620.58 higher over the full 12 months than the average monthly spend during the first four months.

Need

Of the parents who used the NEF, most felt that it reduced their anxieties about money while their babies were ill, and removed barriers to spending time with their children in hospital. None of the small number of parents who knew about the fund but did not make a claim felt that not claiming inhibited their ability to visit their children in hospital.

Some parents identified a gap in the provision of the NEF, commenting that they were unable to claim because their children remained in hospital but were moved to hospital wards outside the neonatal unit. This meant that they became ineligible for the NEF despite their need for financial support remaining unchanged.

Information and support

It is clear that not all parents of children who spent time in the neonatal unit were aware of the NEF, meaning that some parents missed out on claiming either because they never knew about it, or because they had not known about it in time to retain their receipts.

Issues with the clarity of information were also raised, with some parents being unsure about issues including whether they were eligible to claim, where to submit their claims, what they were allowed to claim, and whether both parents were allowed to make claims for a shared trip.

Process of making NEF claims

Parents who made claims were generally satisfied with the process of claiming, with a significant majority finding it easy to fill out the form, submit a claim, and get assistance where necessary from staff.

The main concerns raised by staff and parents about the process of using the NEF related to the formatting of the claims form, some parents needing to travel to other hospitals to submit claims forms, and the speed of processing payments.

4. b. Recommendations

The evaluation gives rise to the following recommendations:

Need

- Explore ways to enable parents to continue to claim from the NEF if their baby is moved to a different hospital ward away from the neonatal unit
- Allow both parents/guardians of a child to claim food and travel expenses when they are both travelling to hospital on the same day

Information

- Consider trialing a number of different methods for advertising the scheme to work out which methods are most effective in encouraging take-up
- Give each parent a clear, detailed information booklet when a child is admitted to the neonatal unit covering eligibility, entitlement and how to claim
- Ensure that all parents are explicitly informed of the NEF on arrival at the neonatal unit and where they can find further information
- Ensure that posters and flyers are clearly visible in all neonatal units
- Ensure that the wording on advertising makes clear that all parents are eligible to apply
- Ensure that the following are made clear to staff and parents, and are applied consistently across neonatal units and health boards:
 - Where to submit a claim
 - What exactly parents are entitled to
 - Whether one or both parents can claim when visiting a child on the same day
 - Whether receipts are necessary to make a claim

Process

- Develop provision of an online claims system to reduce the time that parents spend travelling to finance offices and waiting for claims to be checked
- Develop a more user-friendly claims form (available in online and paper formats) which allows for a larger number of claims to be made at one time
- Widen the range of reimbursement options, so that parents can be reimbursed by the means that suits them best (e.g. cash, cheque or bank transfer)
- Allow all parents to submit their claims at the hospital in which their child is being treated
- Allow the purchase of food outside of hospital grounds
- Consider the possibility of removing the need to provide receipts for the purchase of meals

5. Appendix

Demographics – Parent Survey Respondents

Ethnicity	Percent
Asian/Asian Scottish/Asian British - Pakistani, Pakistani Scottish or Pakistani British	2
White - Irish	4
White - Other British	8
White - Scottish	86
Not available	1
Total	100

Age	Percent	SIMD quintile	Percent
19 or under	0	1	12
20-24	3	2	16
25-29	19	3	26
30-34	40	4	19
35-39	27	5	16
40-44	11	Not available	10
45 or over	0	Total	99
Total	100		

Neonatal unit admissions information – parent survey

When baby admitted to neonatal unit	Percent	Time baby spent in neonatal unit	Percent
Before April 2018	9	> 1 week	8
April-June 2018	17	1-6 weeks	44
July-Sept 2018	31	6 weeks - 6 months	46
Oct-Dec 2018	13	> 6 months	2
Jan-March 2019	29	Total	100
Not known	2		
Total	101		



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