# Sharing roles and control in paediatric low risk febrile neutropenia: a multi-centre focus group discussion study involving patients, parents and healthcare professionals

Jessica E Morgan, PhD1, Robert S Phillips, PhD1,2, Lesley A Stewart, PhD1 and Karl Atkin, DPhil3

Affiliations:

1. Centre for Reviews and Dissemination, University of York, York, UK.
2. Department of Paediatric Haematology and Oncology, Leeds Teaching Hospitals NHS Trust, Leeds, UK.
3. Department of Health Sciences, University of York, York, UK.

Corresponding Author: Jessica E Morgan, jess.morgan@york.ac.uk, Centre for Reviews and Dissemination, University of York, York, UK, YO10 5DD, Tel: +44 (0)1904 321082.

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## Abstract

#### Introduction

Reducing treatment intensity for paediatric low risk febrile neutropenia may improve quality of life, and reduce hospital-acquired infections and costs. Key stakeholders’ attitudes towards early discharge regimens are unknown. This study explored perceptions of reduced therapy regimens in the UK.

#### Methods

Three study sites were purposively selected for their approaches to risk stratification, treatment protocols, shared care networks and geographical spread of patients. Patients aged 13-18 years, parents of children of all ages and healthcare professionals participated in focus group discussions. A constant comparison analysis was used.

#### Results

32 participants spoke of their different roles in managing febrile neutropenia and how these would change if reduced therapy regimens were implemented, how mutual trust would need to be strengthened and responsibility redistributed. Having identified a need for discretion and a desire for individualised care, negotiation within a spectrum of control allows achievement of the potential for realised discretion. Non-attendance exemplifies when control is different and families use their assessments of risk and sense of mutual trust, along with previous experiences, to make decisions.

#### Conclusions

The significance of shared decision making in improving patient experience through sharing risks, developing mutual trust and negotiating control to achieve individualised treatment cannot be underestimated.

Keywords (4-6): paediatric, oncology, febrile neutropenia, qualitative

## Introduction

Febrile neutropenia (FN) is the commonest life-threatening complication of children’s cancer treatment, occurring at a rate of 0.75 episodes per 30 days of neutropenia and 0.15 per month of chemotherapy exposure.[1, 2] Around 3% of children with cancer will die of an infection during treatment.[1, 3] However, many episodes have no significant sequelae, with just 0.1% of low risk febrile neutropenia (LRFN) episodes resulting in intensive care admission or death.[4, 5] Many risk stratification tools have been developed in an attempt to differentiate groups at high and low risk of complications.[6] In the UK, the most commonly used tool to define low risk febrile neutropenia (LRFN) is the modified Alexander rule.[7, 8] Despite the introduction of National Institute for Health and Care Excellence (NICE) guidelines in 2012, FN management in the UK varies, though all centres provide at least 48 hours of inpatient care and intravenous antibiotics.[9–11] NICE guidelines recommend that empiric antibiotics for FN are stopped in stable patients on resolution of fever, irrespective of neutrophil count, and national audits confirm that this is standard practice for the majority of patients.[8, 9]

Reducing treatment intensity for LRFN has been suggested as a way to improve quality of life, reduce hospital acquired infections and reduce healthcare costs.[12–15] A systematic review found reduced duration of admission for LRFN was safe, although it did increase the readmission rate.[5] It also suggested that reduced therapy options may not be acceptable to families and healthcare professionals. Attempts were made to understand these challenges through an exploration of the qualitative literature, but there is little material specifically about paediatric FN care. Hence questions remain about key stakeholders perceptions of early discharge in paediatric LRFN.[16]

This study explored experiences of reduced therapy regimens, seeking perspectives of patients, parents and professionals in UK paediatric haematology and oncology services. It examined decision-making about strategies, aiming to identify factors involved in decision-making and the context in which people make choices. It investigated similarities and differences between groups and considered how these might be aligned to provide an acceptable service for all. One main theme, the quest for certainty, has already been reported.[17] This paper presents the remaining study findings.

## Materials and methods

NHS Research Ethics Committee (ref 15/YH0208) approval was obtained.

### Study sites

Three study sites were purposively selected for their approaches to risk stratification, treatment protocols, shared care networks and geographical spread of patients, as identified within national FN audit data. Key collaborators at each centre were then approached through Children’s Cancer and Leukaemia Group networks. The centre characteristics are outlined in Table 1.

### Participants

Participants were eligible to participate if they were receiving or within six months of completing potentially curative treatment, and did not fall into a ‘high risk’ diagnosis defined by the modified Alexander rule.[7] Multiple members of the same family were eligible to participate. Participants were identified and approached by the local team, with professionals invited through email and team meetings. The authors then contacted participants to establish rapport and make them aware of the study’s aims and objectives, and of the authors’ background. Travel expenses and a £20 voucher were offered, in line with INVOLVE guidelines.[18]

### Focus group discussions

Four focus group discussions were planned at each site:

* Patients, aged 13-18 years
* Parents of children, aged under 13 years
* Parents of teenagers, aged 13-18 years
* Professionals (doctors and nurses working with paediatric FN)

It was not possible to recruit groups for patients or parents of teenagers at two centres; a total of 8 focus group discussions were held, each with 3 to 7 participants. Discussions lasted a median of 72 minutes (range 45–86 minutes). Topic guides are provided in Supplemental file 1. All groups were moderated by one author, a female PhD student with a clinical background and postgraduate training in focus group moderation, with an assistant. Discussions were audio recorded, transcribed, and a research diary kept.

### Analysis

Codes were iteratively identified through repeated reading by one author with input from another. A constant comparison approach was used to combine the material. Within each group, we examined characteristics of individuals, with particular focus on prior experiences of FN, and how these influenced the frequency and quality of codes. We then triangulated across centres and stakeholder groups, analysing codes and concepts in relation to other groups. Codes were linked through mapping for each group and encircling themes were identified. It was at this inter-group analytical stage that the voices of each group of participants were considered and the similarities and differences identified. Consequently, the data obtained specifically through the triangulation of centres and participant groups were explicitly considered and explored. Combining the two stages we produced a network of codes and mapped themes to form the final framework. Following presentations of the findings, participants confirmed the credibility of the analyses as an accurate reflection of their experiences and perceptions.

## Results

The characteristics of the eight focus groups and thirty-two participants are outlined in Table 2. A map of the themes and subthemes is provided in Figure 1.

### Attaining mutual trust, sharing roles and responsibilities

#### Professionals’ roles

Professionals’ roles in managing LRFN were clearly defined, with few distinctions between professional, parent and young peoples’ voices.

There was respect and recognition of nurses’ knowledge and experience in supporting patients and guiding medical staff. Community nurses, who provide nursing care to families in their homes (often including intravenous, intramuscular and subcutaneous medication administration, dressing changes, blood sampling and general nursing care), were highlighted by all groups as being particularly busy. Their skills in sampling central venous lines and in the assessment of children were highly valued. Despite work pressures, all groups felt community nurses should constitute key roles within outpatient services.

Distinctions were drawn between junior doctors and consultants. Junior doctors were discussed either functionally or in an unfavourable tone, considered less able to manage children appropriately, needing stricter protocols, and less confident in decision-making.

The influence of staff outside haematology and oncology departments varied. For example, some discussions about microbiologists were positive, whilst others were less so.

Within the UK, the care of children with cancer is overseen by one of 20 Principal Treatment Centres (PTCs). For many patients, some of their care (particularly supportive care, and sometimes chemotherapy) is provided in satellite hospitals, closer to home, which are called Paediatric Oncology Shared Care Units (POSCUs). In Centres 1 and 2 professionals’ groups, the roles of POSCUs in the management of LRFN were minimally discussed, generally in a negative fashion. They did not discuss the involvement of POSCU staff in developing future protocols or their roles in future services.

Centre 3 spoke positively of POSCU colleagues, and local services, though they highlighted challenges for the PTC including frequent requests for advice and difficulties that arose when the POSCU’s oncology lead was unavailable.

The opinions of families about FN management echoed those of their centre’s professionals. Within Centres 1 and 2, parents shared that POSCU staff did not know their child, had less oncological knowledge, facilities were unclean and treatment was less effective than in PTCs. These participants stated they found it difficult to identify specialist oncology skills:

“5: nobody could do it cos they’re all nervous about doing anything over there

4: and they said something like the lady that could do ports was off for three days or it was… it was shocking

5: which we found really odd but obviously when we’ve asked the nurses here… they said yeah we do ports all the time, said its nothing to us but when they’ve been other places then they’re asked to train people to access ports… so we though oh ok then it starts to make sense a bit… you sort of get in your mind-set a nurse is a nurse and a doctor’s a doctor and they’ll just get on and do it but obviously with specialisations and things you don’t think of these things …” (Centre 1, parents of over 13s)

Due to concerns about care in the POSCUs, parents in these centres preferred to travel to the PTC for FN treatment, even though this increased travel distances and thus impacted negatively upon their experience of care.

In Centre 3, parents spoke differently of POSCUs. They had formed relationships with POSCU staff, took more responsibility for communicating about their child’s disease and in directing care, taking on an educators’ role and becoming valid team members alongside staff. Participants complained about delays when POSCU staff needed to liaise with the PTC but did not voice a desire to have their child’s FN managed at the PTC. Issues of cleanliness or poor skills were not mentioned other than one issue where the deficiency was allocated to specific individuals.

Considering how roles and relationships would need to be negotiated if early discharge regimens for LRFN were instigated made professionals uncomfortable. One professional described these difficulties particularly well. They discussed how paediatric oncology patients are considered “special” and different from children within other paediatric services:

“really what you’re saying at this point is that in… to a certain respect… if they’re a low risk patient you would treat them pretty much the same as you do a general paediatric patient… and it’s about moving... that shift of your opinion that our patients are ‘special’ ([4] laughs) or susceptible whereas actually what you’re saying is they’re... they’re not. And in which case, you’re moving away from the oncology kind of let’s protect everybody kind of approach to more of a general paediatrics approach of somethings really gotta be wrong in order for us to kind of worry about this child…” (Centre 1, Doctor)

This connects to professionals’ identity as people who care for “special” children. Changing the manner in which these children are treated to be more like “normal” children then brings the professionals’ identity into dispute. Recognising this dilemma provides understanding as to why instigating change in this area has proved problematic.

#### Parents’ roles

Parents described playing three key roles in the care of their children with FN. First, their responsibility to protect their children from acquiring infection. Parents deliberated over decisions including school attendance, socialising, and the influence of siblings on infection risk. They undertook routines to prevent infection, including cleaning and hand-washing, and superstitious behaviours such as keeping a packed hospital bag in their cars in the hope this would prevent FN:

“4: I bleached d)’s bedroom yeah… I became obsessed with…

5: that’s what we… our two youngest, we got them a little bit obsessed with washing hands and things, we had the err… alcohol as you come in the door

1: yeah well my husband insisted on that but nobody liked it

5: and they… [youngest child] would literally take it when d)’s friends came, take it to the door like you can’t come in…

4: [other child]’s gone the other way now, we have to … we have to try stop her washing her hands…” (Centre 1, parents of over 13s)

Secondly, parents identified their roles in performing essential care tasks for their children, including enteral tube feeding, care of central venous line dressings and oral chemotherapy administration. Parents felt these tasks were undervalued by professionals and the degree of responsibility devolved seemed arbitrary. One participant shared that as she was able to deliver oral chemotherapy to her child, then she would be happy to observe him with FN:

“…I’m more than happy to take on that responsibility, I’m taking on so many others with it…” (Centre 2, parents of under 13s)

Finally, parents viewed their role to be to care for their child’s overall health, including physical, psychological and social factors beyond FN. This responsibility drew attention to the broader impact of FN admissions and representing the needs of other family members formed a central tenet of the parent role. The professionals’ groups acknowledged none of these parental roles, but did attribute negative attributes to them: the non-presentation with FN; implying the parental role is in conveying a febrile child to hospital immediately; and disrupting attempts to reduce therapy:

“1: … but again of course its parents, parent group get hold of it and say “oh this is happening, that’s happening, not happy with it”, you have then got to change your policy because you’re not going to get compliance, and that’s a key problem for a lot of these things” (Centre 2, doctor)

Juxtaposing this, parents considered professionals were likely to prevent introduction of reduced therapy regimens through high levels of caution, recognising the responsibility felt by professionals:

“2: well they’ve got a lot of responsibility

4: it’s on their shoulders isn’t it if they discharge you

2: and something happens

Rest: yeah

2: that’s a big deal really isn’t it? So it’s difficult for them…“ (Centre 2, parents of under 13s)

Professionals raised concerns that although they were willing to share responsibility with families, families might be unwilling or untrustworthy. They worried that blame for any adverse outcomes would be assigned to them, despite this renegotiation of responsibility:

“2: … but I think it’s also a balance between we’re very paternalistic... we wanna look after our patients we don’t want them to die which is understandable but also parents and families understanding that if you want to do this kind of thing you actually have to take a bit of responsibility yourself and we’re saying that you know yes this is a low risk thing but there are still very occasional cases where it goes wrong so you have to make… I think we need to maybe move more to care agreements with patients than necessarily dictating what happens to them but there has to be a dual responsibility with us saying this is the evidence, this is what we think but if you’re willing to accept that risk then... you know… then we can do this management pathway… if that’s what people want to do…

[additional discussion]

2: and I think ultimately at the end of the day if it went wrong it would come back to us as our responsibility but we’re kind of... that’s the healthcare system that we’re working in at the moment…people want choice but equally…

3: …no responsibility with it….” (Centre 1, doctors)

The parental responses to increases in responsibility varied. One parent voiced concerns about taking on more responsibility:

“2: …if the parents say we want to take them home and then something happens, I guess, is that on the hospital, is that on the parents…erm… I don’t know” (centre 3, parents of over 13s)

Other parents spoke of how the role of parent to any child involves enormous responsibility and felt primarily responsible for each of their children.

#### Mutual Trust

The concept of mutual trust runs through these discussions of roles and responsibility. To allow redistribution of roles in LRFN management, professionals would need to trust colleagues and parents to undertake additional tasks, whilst parents would need to trust professionals to provide the remaining care.

Between professionals, the degree of trust appears dependent upon their knowledge of each other. In centres with established shared care where PTC professionals are familiar with POSCU staff there was increased trust in POSCUs’ ability to provide FN care. Conversely, for centres with minimal shared care, trust in POSCUs was less clear.

For families, trust in professionals was also dependent upon their familiarity; participants who had regular contact with POSCUs tended to trust the care they received there, whilst those attending POSCUs infrequently were less confident. Participants managed on a different ward within their usual hospital or cared for by agency staff disliked this experience.

Discussing their usual professionals, parents in centres 1 and 2, were positive about trustworthiness: “…we trust them you know 100% so you just go by what they say …” (Centre 1, parents of over 13s).

Conversely, professionals in these centres spoke negatively of parents (also see above). They struggled to believe parents would present children with LRFN for care appropriately, ensure the administration of medications or identify any acute deterioration at home.

In centre 3, trust was moderated. Parents felt more responsible for their child’s care during LRFN and placed less trust in professionals, guiding them towards what they felt was more appropriate care. Similarly, professionals trusted families to be in contact with them when appropriate and to be able to identify when their child became unwell.

The difference between centres appears partly dependent upon the degree of shared care for LRFN and seems to correlate with the amount of control apportioned to parents. It is unclear what causes these differences – do centres that relinquish more control to families foster increased mutual trust or do centres with more mutual trust increase the amount of control that families have?

### Potential for realised discretion

#### The need for discretion and individualised care

Professionals and families used the *need for discretion* and *individualised car*e to express the need to respond to families’ social settings, including proximity to emergency care, comprehension of FN, prior experiences, and opinions about early discharge. Parents and professionals, however, differ in their approaches to achieving this.

The *need for discretion,* used by professionals, encapsulates a desire to have a single over-arching protocol, where the management of patients with LRFN is generally the same, with small areas of flexibility to adapt to specific situations. Participants desired the ability to break from the strict rigidity of a protocol without the risk of colleagues’ criticism.

The concept of *individualised care*, expressed by parents, related hope for more flexibility than professionals suggested. Parents preferred care created to support the choices of the individuals with options considered alongside parents at key decision points, such as discharge timing.

Parents place emphasis on their own child and family, independent of any other, looking for a service which would best meet that need during individual episodes. Professionals are compelled to consider the care of all children, and a pathway may increase efficiency, reduce the cognitive workload and allow equitable distribution of resource across a service.

#### Negotiation with a spectrum of control

The *need for discretion and individualised care* link to *attaining mutual trust and sharing responsibility* through *a spectrum of control*. When it came to discussing decision-making about LRFN, the need for the amount of control given to each party to be flexible was discussed by all groups, with control changing over time and dependent on the situation. Some families may not wish to have control over decision-making at all.

Professionals expressed a desire to make their own judgements about a child’s FN treatment, alongside a wish to have their responsibility relieved by decisions being made by the protocol. Relinquishing control to the protocol allowed professionals to avoid the risks of colleagues’ criticism or families’ dissatisfaction. Parents recognised this technique and were frustrated by rigid attitudes. Professionals’ position upon this control spectrum derived from their personal attitudes, affected by the clinical situation, past experiences and centre culture.

Regarding the spectrum of control, parents across centres generally noted that there was minimal negotiation about LRFN treatment:

“1: I don’t see that there’s any negotiation with them.

3: no there isn’t” (Centre 3, parents of under 13s)

Parents used passive language in which they were the objects, rather than participants in the decision-making process. This language was mostly used without comment, though one parent expressed anger about her restricted influence:

“…we go with what we’re told to go with, we don’t really, we don’t have any control of how our children are treated at all... you know I mean at one point I said to them, I wanted them to stop the 6MP and not give it to him because that is one of his worse chemos and I was like, he needs a break from it, but his bloods are fine so he’s got to have it so why can you decide when he can stop having it but I’m not allowed to… you know and they ended up having to stop it because the side effects just took over” (Centre 3, parents of under 13s)

Parents considered how they negotiated with professionals about FN management, through recording their own evidence of side effects or ‘presenting their reasons’ for wanting to take a different course. They also discussed how the balance of control changed over time. Parents had felt anxious and unable to participate in decision-making at the beginning of their child’s cancer treatment. However, those who had a longer relationship with services began to question paternalistic decision-making and to contribute to discussions about management:

“3: … in the early stages the doctors said we just did it… I suppose now we’re more confident to discuss with the doctors rather than just accepting whatever you’re told to start with… its more open you know… we’ve been doing it that long so if we’re not quite happy about anything or you know uncertain, is there another way of doing it? Can we go home? Can we do this?” (Centre 1, parents of over 13s)

Some professionals acknowledged the imbalance in the power distribution. They expressed desires to increase care that was sensitive to families’ needs and negotiated between involved parties. However, when asked about negotiating with teenagers, they remained paternalistic. One group spoke about giving criteria teenagers must meet to be allowed home, another participant felt parental opinions were more important than teenagers’:

“1: …eventually I think one has to listen to the parents because although they’re teenagers they are under the jurisdiction of paediatrics so you’d have to work with the parent and again it boils down to convincing the parents that oral antibiotics are a good thing.” (Centre 2, doctor)

The young people themselves stated that they would ask questions about LRFN treatment options, in similar ways to their parents, when trying to negotiate. Some spoke about using their parents as mediators to the discussion, choosing to relinquish control to them:

“Mod: So, say the doctors were saying something and you didn’t quite agree with what they were saying, [gives examples], how would you tackle that?

2: probably just tell my mum.

Mod: and expect her to…

2: talk to them about it.

1: when I’ve been told to like stay and I want to go, I’ve always like been… I’ve always asked if there’s like, is there not another way…erm… and I get told no so I just do what the doctor says…” (Centre 1, Young people)

#### Non-attendance with FN

One facet of FN discussed in all professional groups and two parental groups was non-attendance when a child had a fever, going against current professional advice. Exploring this aspect of decision-making allows understanding of a situation which is different from that planned by service providers.

Professionals’ responses to families who do not attend with FN were almost exclusively negative. Parents spoke of these incidents in a more varied way. Some said they would always attend with a fever. Others, having considered their predominantly negative experiences of previous care, including deleterious effects of admission on their child’s social and psychological health, along with their perceived risks from FN when their child appeared well, had previously decided to observe their child at home rather than immediately presenting to hospital. Indeed, one parent disclosed feeling guilty when she attended with her child:

“1: whereas I knew… there were times when I knew and there were times when I sat there, when they were putting her on antibiotics, thinking I wish I hadn’t come, I really wish I hadn’t come… because I’m going to be in here 48 hours, she’s not going to eat, she’s not going to drink, it’s probably going to end up being long…

4: we’ll be in here a week

5: it’s a week isn’t it?

1: yeah” (Centre 2, parents of under 13s)

Differences in assessing the risks of non-attendance and the relative harms of admissions may well explain the challenges in negotiation between professionals and parents. Professionals may have distorted opinions of the relative risks of non-attendance, as they may be unaware of the number of episodes in which it occurs. This incorrect ‘denominator’ for the risk means they may then consider it more dangerous than families engaging in it.

The issue of non-attendance also links to professionals’ need to feel in control. As the decision about when a child attends hospital is taken primarily by parents, professionals are excluded from this. It is one of the few aspects of FN care where parents can exercise control. If they do decide to attend hospital, parents are choosing to accept the benefits of a hospital admission alongside the harms that accompany it.

## Discussion

In summary, participants spoke of the different roles they undertook in managing LRFN and how these would need to change if reduced therapy regimens were implemented, how mutual trust would need to be fostered and strengthened, and how responsibility would need to be redistributed. Trust was contingent requiring ongoing negotiation.

Having identified a need for discretion and a desire for individualised care, negotiation within a spectrum of control allows achievement of *the potential for realised discretion*. Non-attendance with FN exemplifies when the spectrum of control is different and families use their own assessments of risk and mutual trust, along with their previous experiences, to make decisions about care.

Currently the balance of power when deciding about treatment of LRFN lies with the protocol and professionals, whilst families have minimal input to the care they receive. If families were included within decision-making, some of this control would be relinquished to them. In conjunction with this control comes the responsibility for the consequences of the decision taken.

We suggest shared decision making (SDM) as an appropriate next step in overcoming paternalism and determinism, recognising differences in focus and beginning to respect the rights of patients to have autonomy over their healthcare decisions. The essential features of SDM are the sharing of information about treatment options, their potential risks and benefits, identifying the patient’s key values and priorities, and then patient and professionals working together in partnership to select the most appropriate option for the individual, based on the best available evidence.[19]

Participation in SDM has been found to improve patients’ quality of life, increase knowledge, and reduce the degree of decisional conflict experienced.[20, 21]Though few studies have found strict clinical benefits, this is perhaps not the aim of SDM, given these are usually situations with equipoise.[22] Instead, patient centred outcomes can be considered as important as purely clinical ones.

With the current changes to health care prioritising the right for patient choice and involvement in their own healthcare, SDM is an increasingly prominent policy feature.[23–25] Despite this, medical paternalism, including retaining power over information and control over treatment pathways, remains the predominant method of healthcare decision-making.[26, 27] Professionals may feel they practice SDM, but research shows they often do not discuss patient values or provide accurate representations of options and risks to patients.[28] Patients report a desire to receive more information and be more involved in treatment decisions, as demonstrated in our current study.[29]

There are many challenges to implementing SDM. Professionals can feel that sharing their lack of certainty may jeopardise patients’ trust, thus undermining the paternalistic nature of medicine.[26, 30] Counter to this, through sharing uncertainty, professionals may instead create a more balanced power dynamic with patients and thus allow a more equal share in decision-making.[31]

Another challenge is that patients may weigh risks differently to professionals and autonomously choose the ‘wrong’ option.[20, 26, 32] Indeed, studies have found that patients enabled through SDM to make healthcare choices, often reduce the amount of intervention that would have been suggested by clinicians. The lack of paternalistic control over such decisions can be disconcerting for clinicians, particularly when they feel that there is a ‘correct’ choice.[26]

Families are also concerned about making the ‘wrong’ choice. Participants worried about potential negative effects of particular choices and the increased accountability that would come with reduced therapy options. This was more prominent for some participants than others.

The desire for SDM seems influenced by trust. Patients who show unquestioning trust in their clinicians are more likely to be passive in decision-making, where as those with moderate to high levels of trust prefer a SDM approach.[33] This seems to fit with the findings of our study. Participants with increased knowledge and experience of FN tended to be more keen to be involved in SDM, consistent with other literature.[34]

Researchers have also found professionals who trust their patients and believe in their competence to understand and make decisions are more likely to engage in SDM.[34] As demonstrated by Centre 3’s professionals, who showed a more positive attitude to parents and their competence felt more willing to engage in discussions about early discharge in LRFN.

The main strengths of this work lie in its inclusion of new voices in the discussion of febrile neutropenia across multiple centres. Meanwhile the most significant limitations relate to the recruitment difficulties for certain groups, namely young people, ethnic minority backgrounds, different family structures, and those with more limited resources, where we acknowledge that social disadvantage can make episodes of febrile neutropenia more difficult to manage for families. These recruitment difficulties persisted despite attempts to mitigate this using appropriate remuneration of participants. As such, we recognise that this study represents a relatively small number of participants, though it explores their perspectives in depth. Small focus groups can lead to limitations in the extent of discussions and can be more acutely affected by shy or domineering participants. These issues are discussed further within our previous paper.[17] We continue to advise that further work is done to attempt to capture the opinions of these under-researched groups, through methods such as online interactions and translated interviews.

One key strength not already discussed is highlighted within this manuscript. This is the strong rapport created within the focus groups, as demonstrated in the occurrence of discussions of non-attendance with FN within parental groups, where participants felt safe to discuss this relatively prohibited behaviour.

In conclusion, the significance of shared decision making in improving the experience of all involved through sharing risks, developing mutual trust and negotiating control to achieve individualised treatment of paediatric LRFN cannot be underestimated.

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## Figure Legends:

Figure 1 – Map of themes