


What Happens When you Ask for Feedback? Anticipating and Addressing Challenges Can Be Effective for Eliciting Parents' Views About Their Critically Ill Child's Retrieval to Paediatric Intensive Care

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Victoria Barber, PhD¹, Ruth Evans, PhD¹, Padmanabhan Ramnarayan, MD^{2,3}, and Jo Wray, PhD on behalf of the DEPICT study team^{1,4} 

Abstract

User feedback is an important element of health-service evaluation and can be used to improve services but can be difficult to obtain, particularly in acute care situations. As part of a national study, we explored stakeholders' perspectives on paediatric critical care retrieval processes through questionnaires and interviews. Obtaining feedback in a highly charged, stressful and busy paediatric intensive care unit (PICU) environment is fraught with difficulties so we aimed to optimise each stage of data collection by being both proactive and reactive. Patient and public involvement occurred throughout and engagement with sites and supporting local research staff to approach and recruit families were prioritised. High-quality study materials were developed to reduce local staff burden and promote and maintain study awareness. We describe strategies used and what worked/did not work. We suggest approaches for optimising elicitation of parents' experiences in difficult circumstances, highlighting the importance of engagement and commitment of PICU staff.

Keywords

retrieval service, paediatrics, intensive care, service user feedback

Background

Learning from patients about the care they have received is crucial for improving health-care services (1). A number of mandatory approaches for collecting patient experience data have been established within the National Health Service (NHS) in England, including the Friends and Family Test (FFT) (2). Local organisations also collect feedback through a variety of different methods such as surveys, patient forums, and informal feedback from Patient Liaison Services (1). Despite FFT being the largest source of patient opinion worldwide, it provides limited information and, in the absence of any further data, cannot drive change (3). Collecting actionable feedback and making changes based on the findings to improve services remains a challenge.

Within paediatric services, parents are often asked to provide feedback about their experiences of care received by their child, frequently because children are unable to provide feedback themselves due to their age, cognitive

ability and/or health condition (4). Ideally, however, both parents and children and young people (CYP) should be asked to provide feedback as they experience the same situation differently (5).

Since the centralisation of paediatric intensive care services in the United Kingdom (UK) (6), specialist paediatric critical care transport teams (PCCTs) have been

¹ Centre for Outcomes and Experience Research in Children's Health, Illness and Disability (ORCHID), Great Ormond Street Hospital for Children NHS Foundation Trust, London, UK

² Children's Acute Transport Service (CATS), Great Ormond Street Hospital for Children NHS Foundation Trust, London, UK

³ Paediatric Critical Care, Imperial College, London, UK

⁴ NIHR Great Ormond Street Hospital Biomedical Research Centre, London, UK

Corresponding Author:

Jo Wray, Great Ormond Street Hospital for Children NHS Foundation Trust, Great Ormond Street, London WC1N 3JH, UK.
Email: jo.wray@gosh.nhs.uk



established to travel to local hospitals to assist in stabilising and transferring critically ill children to regional paediatric intensive care units (PICUs) (7). In the UK approximately 5000 critically ill children require emergency transport to PICU every year (8). Stresses associated with a PICU admission are well documented, including long-term psychological trauma (9–11). Patients' and families' experiences associated with critical care *retrieval* are less well understood, but parents of sick children have described the process of PICU retrieval as 'the worst journey of their lives' (11,12).

To date feedback about the retrieval of critically ill children has been sought via questionnaires developed by individual services, given directly by PCCTs to families, and local audit data indicate that return rates have generally been low (<20%). Specific reasons for low response rates in this context are unknown, but possible reasons are that staff may feel it inappropriate to approach families at a time of great stress and/or families may be simply too anxious to provide feedback. Timing of the approach to families is clearly extremely important.

The DEPICT Study

The DEPICT study (**D**ifferences in access to **E**mergency **P**aediatric **I**ntensive **C**are and care during **T**ransport) was a national multi-centre study (13), one aim of which was to understand experiences of the transport of critically ill children from the perspectives of different stake-holders (patients and families, and healthcare staff from referring hospitals, PCCTs and PICUs). In this article, we reflect on the methods used within DEPICT to address this aim in relation to the experiences of patients and families, strategies employed to increase user-engagement and assessment of the feasibility and acceptability of eliciting feedback within a critical care setting.

Study Context

There are 24 PICUs located across 21 NHS Trusts in England and Wales and all participated in the study. Within the relatively small PICU community, there is a well-established network of existing relationships that helped to facilitate the recruitment of committed site Principal Investigators and provided multiple opportunities for the central research team to engage and network with staff, including attending meetings of the Paediatric Intensive Care Society and Acute Transport Group. The PICUs have a history of working collaboratively on successful multicenter trials (14,15) and have the infrastructure to participate in large studies, although variability exists in resources available for research across the sites.

A detailed description of the methods is provided in the final study report (16).

Anticipated Challenges and Strategies to Increase User Feedback

In view of the historically low uptake of opportunities to provide feedback about PCCTs and the nature of the situation in which we were asking families to do this, we anticipated a number of challenges. A range of strategies was therefore employed proactively to increase user engagement at each stage of the study (Table 1).

Questionnaire Study

Each PICU team kept a log of eligible participants and outcomes of decisions to approach and consent.

Recruitment. Recognising that families of critically ill children are likely to be highly stressed, written consent was deferred to a time after PICU admission judged to be suitable by the clinical team, although we recommended speaking to families within the first 24–48 h to facilitate recruitment of short-stay admissions. Parents were offered a number of options to facilitate questionnaire completion based on evidence that providing participants with a choice of methods for completion increases response rates (17–19).

To increase saliency a range of visual cues was used to enhance awareness of the study in the PICUs (Figure 1). Particular attention was given to the 'look and feel' of the questionnaire to increase families' perceptions of study integrity. The questionnaire was developed specifically for this study and was based on a review of relevant literature and existing questionnaires used by retrieval teams to gain feedback, as well as the experience of the study team, steering group and parent representatives to further inform content and format. The questionnaire was piloted with six families from two PICUs to check coherence, clarity and acceptability.

Recruitment of Under-Represented Families. Bereaved families are often under-represented within health services research but evidence suggests that participation can be a positive experience for parents, allowing them the opportunity to reflect, remember their child and help improve the experience of subsequent bereaved families (20,21). Excluding bereaved families would also introduce selection bias. Families who do not speak/read English are also often under-represented and these families tend to have a poorer experience of health care (22). Additional measures were taken to facilitate the inclusion of these groups (Table 1).

Table 1 summarises other strategies used for subsequent stages of the study which involved re-contacting and recruiting families for interviews (including children and bereaved parents), collection of follow-up data by questionnaire at 12 months and attendance at stakeholder workshops. PICU staff were also invited to provide feedback on the study set-up, recruitment and support from the central research team via a brief, anonymous questionnaire.

Table 1. Anticipated Challenges of Recruitment and Strategies Used to Increase User Engagement.

Challenges	Strategies
Standardising study administration across multiple sites	<p>Site initiation visits at each site prior to study commencing (CI and central study researcher), to discuss study protocol and perceived potential barriers to or concerns about recruitment; opportunity to build relationships with RNs and PI at each site to encourage frequent future contact for eligibility enquiries.</p> <p>Screening log template was provided to each site where details of all children who met inclusion criteria were entered and assigned a study number. Logs were sent regularly to central study researchers to monitor recruitment</p> <p>Each site provided with clear and detailed Standard Operating Procedures</p> <p>Two full-time researchers were available to answer RNs queries (by email or telephone)</p> <p>Study team attended critical care meetings to maintain engagement and share best practice</p> <p>Quarterly newsletters sent to each site to update them on study news and celebrate successes, e.g., recruitment numbers</p> <p>Each site was provided with pre-packed envelopes including study materials to reduce site administration burden and facilitate easy completion: a pen; free post envelope; study information leaflet; consent form; paper copy of questionnaire</p>
Recruiting families in a critical care setting: recognition that parents may be experiencing high levels of stress	<p>Consent deferred to a time judged to be suitable by staff</p> <p>Experienced and qualified staff obtaining consent</p> <p>Encouraged completion of questionnaire on PICU to reduce recall bias and increase questionnaire return rate</p> <p>Multi-mode options of completion: paper version; online via study link including a speak-aloud option to facilitate completion for participants with low literacy levels; by phone with study researcher</p> <p>Range of visual cues used to enhance awareness of study in PICUs: study posters; study mugs; study pens.</p> <p>Interested families provided with a pre-packed envelope with everything needed to complete questionnaire (see above)</p> <p>Families had choice for returning questionnaire: via Royal Mail (using free-post envelope) or a bespoke post box (designed to represent an ambulance) supplied to each PICU</p> <p>Considered length of questionnaire to reduce burden (eight pages, 10–15 min completion time)</p> <p>Questionnaire piloted with families on PICU to check coherence, clarity and acceptability</p>
Recruiting bereaved families into questionnaire study	<p>Deferred consent to 6–8 weeks after child's death</p> <p>Personalised letter sent from site PI, managed in accordance with each PICU's local bereavement policy</p> <p>Adapted study materials</p> <p>Sites provided with bereavement materials upon request; printed on yellow paper so that they could be easily distinguishable from the other questionnaires.</p>
Recruiting non-English speaking families into questionnaire study	<p>Study materials translated into five languages (Bengali, Gujarati, Punjabi, Urdu and Polish), based on most frequently spoken languages (after English) in England and Wales from 2011 census data (ONS, 2011)</p> <p>Language translation company and volunteers used to undertake forward translation and proof reading of all study materials</p> <p>Volunteers and other hospital staff 'sense checked' questionnaires, providing further checks for accuracy and meaning</p>
Recruiting families into interview study	<p>Deferred contacting families to invite them to participate in the interviews (2–3 months after their child's admission to PICU)</p> <p>Option to complete the interviews face-to-face in a location of their choice (home, workplace and cafe) or over the telephone.</p>

(continued)

Table 1. (continued)

Challenges	Strategies
Recruiting bereaved families into interview study	Adapted communication (via email), to acknowledge the bereavement and to sensitively enquire whether they wished to remain part of the study
Recruiting CYP into interview study (recognising that most would have been sedated/ventilated during transportation and therefore unable to remember experience and/or under 5 years of age)	Age-appropriate information sheets provided Approach via parents some time after PICU stay Offer of having a family member present for support Use of creative methods to engage CYP
Re-engaging families 12 months after initial recruitment	Families asked to provide preferred contact method (email or telephone or both) at initial consent stage Personalisation of communication via email, telephone or post Offer of multi-mode options of completion (online or postal) Postal copies included a cover letter thanking them for agreeing to participate, instructions for completion and return of the questionnaire, prelabelled paper questionnaire with unique study number and a free post envelope The email invite included a link to the online questionnaire, a unique study number and instructions for completion A reminder email was sent to non-responders 2 weeks after initial invite Families who provided a telephone contact only were contacted to ask to provide an email address or be sent a postal copy if preferred – up to three telephone contact attempts were made at different time periods Email addresses that were incorrect: if a telephone contact was provided a call was made to rectify the email address or to be sent a postal copy if preferred
Inviting families to attend a face-to-face study workshop to share preliminary findings and elicit feedback	Personalisation of email invitation Short email invitation thanking families for their previous participation in the study and describing the value of their involvement so far and how they can help further Customised online event page was created where families registered attendance Two workshops were held in different geographical locations Travel reimbursed for each family member that attended Shopping voucher for each family member that attended

CI, Chief investigator; RN, Research nurse; PI, Principal investigator; PICU, Paediatric intensive care unit; CYP, children and young people.

Effectiveness of Methods Used to Improve Recruitment

Figure 2 and Supplementary Figures S1-S3 indicate the numbers of families who were approached and participated at each stage of the study. Reasons why families were not approached or recruited are shown in Table 2.

Questionnaire Study

Based on the number of children transported to PICU and data about response rates in questionnaire-based research (23), we estimated receiving 800–1000 completed questionnaires (16%–20% response rate). During baseline data collection (January 2018–January 2019), 4558 families were identified as eligible for participation (Figure 2). Of 3439 approached for consent, 2838 consented to the initial questionnaire, of whom 2133 returned at least a partially completed questionnaire (47% of those eligible overall; 62% of

those approached for consent), more than double the number expected.

On the screening logs 110 families were identified as non-English speaking. Ninety-three families were not approached due to lack of available interpreter services/appropriate translated materials; 17 were given an alternative language pack and 6 completed questionnaires were received. One site reported that two families declined participation because of translation errors of the Urdu and Bengali questionnaires which, for those with low literacy levels, were difficult to comprehend.

Interview Study

We planned to recruit approximately 50 parents, a sufficient number to capture the range of parents' experiences across the different models of care delivery (24). A large number of families initially consented to being contacted about interview participation (Figure S1) of whom 100 families were



Figure 1. Examples of visual cues used to enhance awareness of the study in the PICUs.

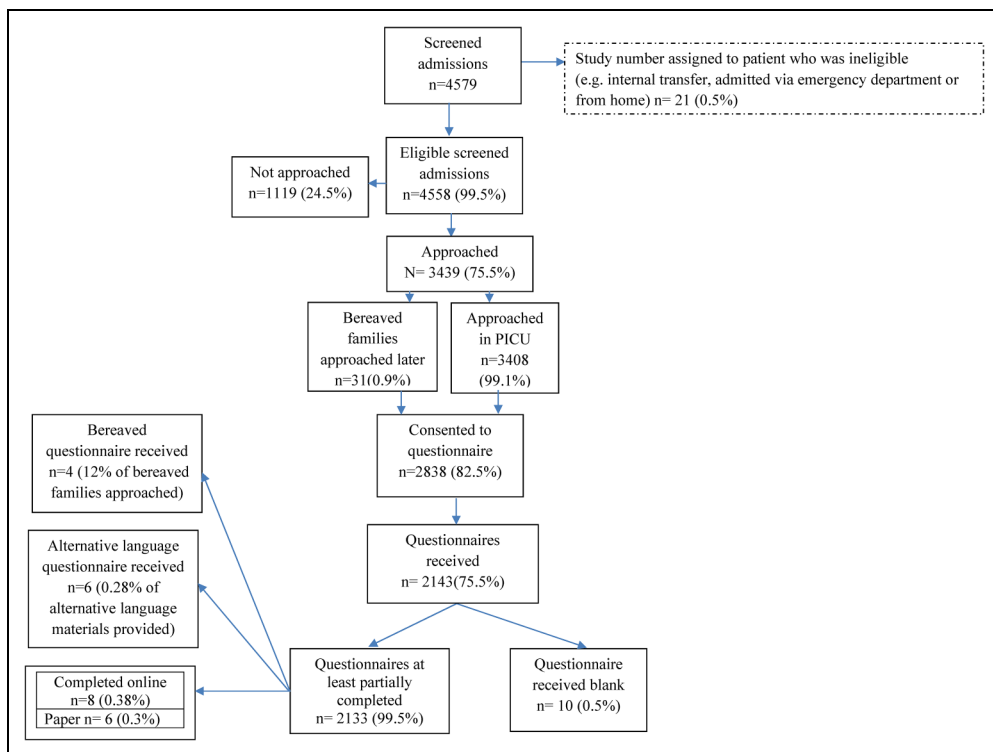


Figure 2. Flow diagram of participants recruited into the questionnaire study.

Table 2. Reasons Families Were not Approached or Consent was not Received for Participation.

	Number (%)
Reasons families were not approached	1119 (100)
Child died prior to approach	76 (6.8)
Child discharged prior to approach	530 (47.4)
Unable to discuss with parents	366 (32.7)
Parents not present	32
Clinical situation	13
Complex social situation/no parental responsibility/in care/non-accidental injury	69
Language barrier/literacy difficulties	64
Parent without mental capacity to consent	2
Other	17
Not specified	169
Other	8 (0.7)
No reason provided	139 (12.4)
Reasons why no consent was received	601 (100)
Consent not sought by health care professional after initial approach	31 (5.1)
Consent criteria not met/language/literacy/mental capacity	21
Social reasons	4
Parent ill health	3
Parents' emotional state	3
Consent sought but child was discharged before	119 (19.8)
Consent refused by parent	106 (17.6)
GDPR (general data protection regulation) related	2
Health status of child	4
Parents did not feel involved enough in transfer (e.g., not in ambulance)	30
Not interested in research	21
Parents report being too emotional	4
Parents said language/literacy not sufficient	8
Parents said too busy	5
Prior participation and not interested in repeating	32
Consent declined – no reason given	181 (30.1)
CYP died before consent given (31 approached via bereaved protocol)	37 (6.2)
Consent not obtained	127 (21.1)

contacted and 30 interviews were completed, at which point no new evidence was being obtained.

We hoped to recruit 20–30 CYP but were unsuccessful and recruited none. Finding eligible children was challenging due to the young age (<2 years) of most CYP transported. Two interviewed families whose child was eligible to participate were asked if their child would like to participate: one declined as the parent was concerned about the process of revisiting the event and one did not respond after initially expressing interest.

12-Month Follow-up Questionnaires

We originally anticipated receiving 200–250 questionnaires based on the estimated original questionnaire responses of 800–1000. We received 520 completed questionnaires,

representing 21% of those who consented at baseline to receive follow-up questionnaires but 29% of those who could be contacted and sent a follow-up questionnaire (Figure S2).

Stakeholder Workshops

Our aim was for approximately 30 stakeholders to attend workshops (5–7 families and 5–7 clinicians at each of two workshops) (Figure S3). For the first workshop (12/3/20) six parents registered to attend but only three attended on the day; those who did not attend cited the COVID-19 pandemic. The second scheduled workshop was cancelled due to COVID-19.

PICU Staff Feedback

Twenty-seven surveys were received from 16/21 (76%) Trusts. Results of measures put in place to support staff are summarised in Figure S4. Study set-up, study materials and support received from the research team were positively evaluated by most staff. They highlighted the difficulty of approaching families when there was a language barrier and suggested having finances available to use translators would have been useful to encourage non-English speaking families to participate. Suggestions for future collection of parent feedback included a shorter, anonymous questionnaire with options for completion including the provision of tablets with preloaded surveys.

Discussion

User feedback is an important element of health service evaluation but historically has proved difficult to obtain for PCCTs. We have reflected on our methods and effectiveness of collecting feedback to inform learning for both future research and routine collection of patient experience data. It is clear that a large proportion of families of CYP transported to PICU are willing to provide feedback about their experience. Our findings suggest it is feasible and acceptable to acquire user feedback within a critical care setting but it requires careful consideration about how and when to approach parents. Of note, in our study parental ratings of the transport service were generally very high, so motivation to provide feedback may also have been influenced by the experience they had and a desire to thank the team.

Recognising that obtaining feedback in a highly charged, stressful and busy critical care environment is fraught with difficulties, we tasked ourselves with optimising each stage of the process by being both proactive and reactive. We placed great importance on the role of patient and public involvement (PPI) (25), working closely with expert parents and professionals and ensuring that PPI was embedded in the research. Two parents and three external PICU/transport staff were members of the central research team

and were integral to each stage of the project design, implementation and evaluation of progress.

Throughout the study, engagement with sites and supporting local research staff (directly and indirectly) were prioritised. The central research team was responsive to local staff need, initiating regular (initially weekly then monthly) contact and being available to answer questions about eligibility and recruitment and requests for support. We also prioritised the development of high-quality study materials, pre-packed questionnaires and appropriate study cues which, while resource intensive for the central research team, helped to reduce local staff burden and promote and maintain awareness of the study across the units. We believe our higher than anticipated rates of approach and recruitment are testament to our strategy and to the commitment and engagement of the local PICU teams. Previous studies have identified local 'gate-keeping' in terms of who is or is not approached (26) but we suggest that adequately resourcing site engagement helps to reduce this.

The high response rate also suggests families found the questionnaire content relevant and acceptable, highlighting the importance of engaging with families during development and piloting to ensure the feasibility and acceptability of what we were asking families to do. However, although families could complete the questionnaire online, the majority opted for paper completion, possibly because that was their preference or because access to the online questionnaire was not efficient enough. Providing an additional method of accessing the e-questionnaire such as on a tablet-computer while in PICU may have increased response rates. Improving online response rates for future research or routine feedback would be more efficient in terms of preparation and data input. However, the evidence about offering mixed-mode methods of collecting questionnaire data to increase response rates (17–19) suggests families should still be offered options for questionnaire completion.

Despite our successes, there were some areas in which we did not do well. Although study materials were translated into five languages, we recruited very few non-English speaking families. Many were not approached as no interpreter was available and we did not have translated materials for all languages. Furthermore, during times of distress and anxiety cognitive processing may be impacted as well as literacy levels (11,27). Having study information and questionnaires available on a tablet computer with read-aloud functionality for alternative languages may be a cost-effective and logistically feasible way to improve response rates among this group in future. We also recruited a very low number of bereaved families. Not all families whose child died in PICU were approached. It is unclear why this was, but sites may not have been clear about the procedures of the bereaved protocol or felt uncomfortable implementing it. Bereaved families are frequently excluded from research (20,21) and may not be asked about their experiences yet

they are often willing and want to participate and this needs to be addressed in future.

A sufficient number of parents were interviewed but we did not recruit any CYP, primarily due to their young age and because most were sedated and ventilated for the transport. However, a few CYP were willing to provide feedback by completing the questionnaire so a CYP-specific questionnaire for later postal completion might have increased engagement with them. Furthermore, completing a questionnaire rather than participating in an interview may have reduced parental concerns over the effects on their child of revisiting the event.

Collecting follow-up data is important but challenging (28). Re-engaging with families 12 months after their initial recruitment was not always feasible which meant the response rate was lower than anticipated. Re-engaging families is resource intensive yet if we want families to complete follow-up measures we suggest the same level of commitment and allocation of resources are required as we were able to dedicate initially. Some strategies we employed, such as personalising emails and sending email reminders, likely increased our response rate but we were unable to use a similar reminder method for those without email addresses who were sent postal questionnaires, where the return rate was lower.

Although our successes with initial recruitment are to be celebrated, they resulted in unanticipated demands on the central research team including an increased number of families to follow up at 12 months; additional time supporting sites and related administration tasks; and additional time pressures related to data entry, cleaning and analysis. Finally, COVID-19 was an unforeseen challenge that we could not overcome in the study time frame. However, using online technologies with materials provided in advance are consideration for future dissemination and elicitation of participant feedback.

Conclusion

We used a number of effective strategies for recruiting families and, learning from our experiences, suggest approaches to maximise response rates for future research and/or routine collection of patient experience data (Box 1). Importantly, despite the stressful situation they were in, a high proportion of families were willing, and wanted, to provide feedback. The engagement and commitment of PICU staff were crucial for maximising parental participation and should not be under-estimated when developing strategies for asking parents for feedback. How to engage under-represented populations as well as CYP themselves needs to be addressed and understanding and facilitating families' preferences are important considerations in maximising feedback.

Box 1. Strategies for increasing response rates to parent experience questionnaires

- Clear information about the purpose of the questionnaire and how the information given will be used to improve the service
- Questionnaire should be short
- Multi-mode methods for completion offered
- Online versions available on tablets for completion before discharge and via an online link to complete later
- Paper versions in booklet format, printed in colour and on high quality paper; stamped return envelope for confidential return
- Available in multiple languages with speak aloud functionality
- Options for return of questionnaire (post-box on PICU, free post envelope)
- Assurances about anonymity and security of the data
- Opportunity to provide free text comments
- Indication of how previous information has been used – ‘you said, we did’
- Contact details for the team if they want to discuss anything further
- Thank the participant!

Author Contributions

PR was the Chief Investigator for DEPICT. PR and JW wrote the protocol (with other team members). RE developed the patient information resources. RE and VB led the acquisition, analysis and interpretation of the data reported in this manuscript. VB drafted the manuscript and all authors critically reviewed and approved the final version.

Ethical Approval

This study was approved by the National Research Ethics Service – London Riverside Committee (ref: 17/LO/1267).

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ORCID iD

Jo Wray  <https://orcid.org/0000-0002-4769-1211>

Statement of Human and Animal Rights

All procedures in this study were conducted in accordance with the National Research Ethics Service approved protocols.

Statement of Informed Consent

All participants provided written consent prior to their participation in the study, which included consent for anonymised data to be published.

Supplemental Material

Supplemental material for this article is available online.

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