


ORIGINAL RESEARCH

Measuring patient and carer experience related to paediatric gastrointestinal endoscopy: multicentre questionnaire study

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ABSTRACT

Background The Paediatric Endoscopy Global Rating Scale (P-GRS) is a quality improvement tool used in the UK. An important aspect of this includes regular surveys on the patient and/or carer's endoscopy experience. The aim of our study was to design and implement a patient/carer experience questionnaire.

Methods This questionnaire was designed to obtain feedback on patient and/or carer satisfaction with their endoscopy experience. Question selection was based on relevant measures in the endoscopy Global Rating Scale, with input from clinical governance, Patient Advice and Liaison Service and a hospital youth forum. This was distributed to patients and/or carers in three UK paediatric endoscopy services during six surveys between 2013 and 2018. Data were then collated and analysed on Microsoft Excel for Office 365 MSO (16.0.11901.20070).

Results Overall, 830 endoscopic procedures occurred during the six survey periods. 270 questionnaires were returned. Feedback from the questionnaires were mostly positive (overall satisfaction rated 'excellent' or 'good' was seen in 87% of responses) but also identified areas of improvement, such as in managing postprocedure pain and having a separate space for adolescents for preprocedure discussions. Improvements in satisfaction scores were noted in one unit over time, particularly in preprocedure preparation (from 86% to 100%), and overall satisfaction with endoscopy experience (81%–100%).

Conclusion All three paediatric endoscopy services found this questionnaire useful in identifying areas needing improvement and in demonstrating compliance with measures within the P-GRS quality of patient experience domain. Further work includes exploring ways to increase response

Significance of this study

What is already known about the subject?

► Paediatric gastrointestinal endoscopy is an increasingly common procedure performed in children in the UK. The paediatric endoscopy global rating scale (P-GRS) is a quality improvement tool that has been available in the UK since 2017. Quality of Patient Experience is one of the four domains within the P-GRS and obtaining patient feedback regularly is a required measure within this domain. There is little documented on the use of paediatric endoscopy satisfaction questionnaires in published literature, which prompted the need to design a questionnaire locally.

What this study adds

► This is the first questionnaire that has been developed for gathering information on patient/carer experience with paediatric endoscopy services in the UK. The developed questionnaire was helpful in highlighting areas of service improvement locally following its use in three paediatric endoscopy services.

How might it impact on clinical practice in the foreseeable future

► As an increasing number of UK paediatric endoscopy services actively engage with the P-GRS quality and safety framework, the use of this questionnaire could be fed into quality improvement plans within paediatric endoscopy units in the UK thus ensuring compliance with related measures in the patient involvement standard.

rates, as well as developing age-appropriate and electronic versions.

BACKGROUND

Gastrointestinal (GI) endoscopy is an increasingly common procedure performed to investigate and diagnose problems in the paediatric GI tract. Rates of paediatric GI endoscopy have significantly increased over the past decade in the UK: from 83.1 per 100 000 in 2005/2006–2007/2008 to 130.5 per 100 000 in 2012/2013–2014/2015.¹ Thus, it becomes increasingly important to address and measure the quality of patient experience.

The Endoscopy Global Rating Scale (GRS) is a validated quality improvement tool developed by the Joint Advisory Group (JAG) for UK adult GI endoscopy services and has been used since 2005. This online assessment tool has been found to be valuable in reviewing local practice to improve patient experience.²

The British Society of Paediatric Gastroenterology, Hepatology and Nutrition, the Royal College of Physicians of London and JAG have collaborated to launch the paediatric GRS (Paediatric Endoscopy Global Rating Scale (P-GRS)) in 2017. The P-GRS is a quality improvement tool mirroring the adult GRS and has been designed to be relevant for paediatric endoscopy and child-centred care.^{3,4}

The P-GRS looks at four key areas of service delivery: clinical quality, quality of patient experience, workforce and training.^{3,4} Development of a patient/carer experience questionnaire would be integral to understand the patient and carers' experience firsthand, to let patients engage with their care, as well as better address their expectations.⁵

There is scarce literature on paediatric endoscopy experience questionnaire use, prompting our team to develop a questionnaire locally.

METHODS

Questionnaire design

A study involving patient focus groups demonstrated that the Endoscopy GRS did address quality issues that mattered to patients undergoing endoscopy.⁶ Therefore, the design of the 'Patient and Carer Experience of Endoscopy Questionnaire' was based on relevant measures within the Endoscopy GRS's 'quality of patient experience' domain. The questionnaire was then modified following input from the multidisciplinary team at Sheffield Children's Hospital ('unit A', a tertiary paediatric gastroenterology service, which is a stand-alone service that undertakes seven to eight elective paediatric endoscopy lists a week), the Patient Advice and Liaison Service, the local clinical governance team and the hospital youth forum. This also helped determine the most appropriate use of language in the questions.

Ethical approval was not required as this was a service evaluation questionnaire and the local governance committee mandates approval of all patient questionnaire surveys by PALS. The hospital youth forum routinely inputs into service developments at unit A.

The questionnaire was used four times at unit A from 2013 to 2018 and was subsequently shared with teams at Royal London Hospital ('unit B', a tertiary paediatric gastroenterology service that undertakes four elective lists a week, which operates independently of the adult service but as part of the same organisation) and Royal Stoke University Hospital ('unit C', a teaching hospital that undertakes two elective paediatric endoscopy lists a week as part of an integrated endoscopy service within the adult endoscopy department) to ensure this questionnaire could be generalised to a population in different service settings.

Each unit secured approval and registered this as a service evaluation project with their local Clinical Governance Committees before data collection. During its use, minor improvements such as addition of a 'smiley-face' Likert scale and check boxes were made (see online supplementary appendix 1 for the exemplar questionnaire used).

Strategy

At unit A, the questionnaires were distributed by junior doctors in the Paediatric Gastroenterology Team and Theatre Admissions Unit nurses. This occurred over four study periods between 2013 and 2018: December 2013–January 2014 over 5 weeks ('unit A-1'), June–August 2014 over 5 weeks ('unit A-2'), October–November 2016 over 3 weeks ('unit A-3') and April 2018 over 2 weeks ('unit A-4'). For day cases, the surveys were given to patients and their carers on arrival to the Theatre Admissions Unit on the day of endoscopy. For endoscopies done during an inpatient stay, the surveys were distributed to the families after clerking. Families were asked to return their completed questionnaires prior to hospital discharge, and labelled boxes were left in each ward area to collect the anonymised questionnaires.

At unit B, the questionnaires were given to the patient and their carers by junior doctors when being clerked and consenting to pre-endoscopy and then collected before hospital discharge. This was distributed over a period of 4 months (November 2016–February 2017).

At unit C, the questionnaire was modified by the local gastroenterology team into a leaflet, and extra categories were added to reflect the local service setting (unit C's questionnaire is included in online supplementary appendix 2). Extra categories included the role of specialist nurses who routinely counsel patients prior to endoscopy, in addition to the consultant medical review, as well as the experience with play specialists who accompany the patient to the anaesthetic room in the adult endoscopy unit. A question was also added

Table 1 Overview of six questionnaire surveys and summary of overall satisfaction

	Unit A-1	Unit A-2	Unit A-3	Unit A-4	Unit B	Unit C
Time frame of study	5 weeks	5 weeks	3 weeks	2 weeks	4 months	12 months
Total number of respondents	36	59	28	11	58	78
Total number of endoscopies performed during the study period	109	120	46	54	187	281
Percentage of respondents: total number of endoscopies performed	33	49	61	20	31	28
Male	19 (53.8)	26 (44)	13 (46.4)	*	26 (44.8)	39 (50)
Female	13 (36.1)	31 (52.5)	11 (39.3)	*	22 (37.9)	29 (37.2)
Not recorded	4 (11.1)	2 (3.4)	4 (14.3)	11 (100)	10 (17.2)	10 (12.8)
Hospital inpatient case (admitted night before)	0	8 (13.6)	2 (7.1)	2 (18.2)	17 (29)	3 (3.8)
Day case (not admitted night before)	0	50 (84.7)	25 (89.3)	9 (81.8)	41 (71)	71 (91)
Not recorded	36 (100)	1 (1.7)	1 (3.6)	0	0	4 (5.1)
Overall preparation rated as 'excellent' or 'good'	31 (86.1)	48 (81.4)	22 (79)	11 (100)	46 (79.3)	63 (80.8)
Follow-up arranged postendoscopy	24 (66.7)	41 (69.5)	20 (71.4)	10 (90.9)	44 (75.9)	64.1
Overall anaesthetic room experience rated as excellent or good	33 (91.7)	47 (79.7)	22 (78.6)	*	52 (89.7)	*
Doctor's sensitivity and courtesy rated as excellent or good	29 (80.6)	33 (55.9)	21 (75)	10 (90.9)	51 (87.9)	69 (88.5)
Patient dignity rated as excellent or good	29 (80.6)	50 (84.7)	21 (75)	10 (90.9)	54 (93.1)	70 (89.7)
Patient comfort rated as excellent or good	29 (80.6)	48 (81.4)	21 (75)	11 (100)	52 (89.7)	68 (87.2)
Overall experience rated as excellent or good	29 (80.6)	48 (81.4)	21 (75)	11 (100)	51 (89.7)	57 (73.1)

Unit C recorded information for an age group of 16–20 years.

Raw numbers and relative percentages are shown in parentheses.

*Not recorded.

to clarify whether a parent, a patient or both parties completed the survey. The questionnaire was given to the patient and carers when the child was admitted for the procedure onto the day ward and collected prior to discharge. This was distributed over a period of 1 year (November 2016–November 2017) and coordinated by the gastroenterology specialist nursing team.

Findings from all three units were then presented locally to further service improvement.

RESULTS

A total of 270 questionnaires were returned from the six studies, with a range of 11–78 returned from each survey (table 1). This reflected around 37% (range of 20%–61%) of the total number of patients who underwent endoscopy during the study time periods.

Five surveys have shown a similar number of responses between male and female patients (unit A-4 did not record patient demographics). There were relatively more responses from the age group of 13–15 years (median of 32% across all five studies, range 4%–18%), a relatively similar number of responses from the age groups of 3–5, 6–9 and 10–12 years (median of 14%–18% in all three groups, range 9%–22%), and relatively few from the age groups of 0–2 years (median of 8.3%, range 4%–18%) and 16–18 years (median of 10%, range 0%–11%; unit C was also included in the same category of patients aged 18–20 years) (figure 1). In addition to the standard questions, unit C found that 57.7% of their surveys were answered by the parent/carer alone, 30.8% by both parent/carer and patient, and 10.3% by the patient themselves.

Responses have mostly been positive among all six studies: the overall experience was rated 'excellent' or 'good' by at least 75% of respondents, and in one up to 100%. This was echoed in other care domains, such as preprocedure preparation (67% or more rated excellent or good), comfort and maintaining dignity (75% or more rated excellent or good).

Repeated use of the questionnaire by unit A showed improvement in scores, particularly in overall preprocedural preparation satisfaction (86.1% in unit A-1 to 100% in unit A-4), number of families where follow-up arrangements were communicated (67%–91%) and patient/carer overall satisfaction scores (81%–100%).

Throughout all six surveys, there were some questions for which respondents did not provide an answer for. The average non-completion rate for each question was 13%, ranging from 0% to 85% (individual data from all three centres are included in online supplementary appendix 3).

Free text feedback are summarised in box 1.

DISCUSSION

Experience of patient satisfaction questionnaires in paediatric endoscopy literature

Considering the increased need for high-quality paediatric endoscopy, there is little documentation in the literature regarding the use of patient/carer experience questionnaires. The paediatric endoscopy group from Sainte Justine Hospital in Montreal distributed 157 patient satisfaction surveys and identified the need to improve preprocedural patient information, as well as postprocedure analgesia within their service.⁷ A group from St. Christopher's Hospital for Children in Philadelphia conducted 47 phone interviews with families

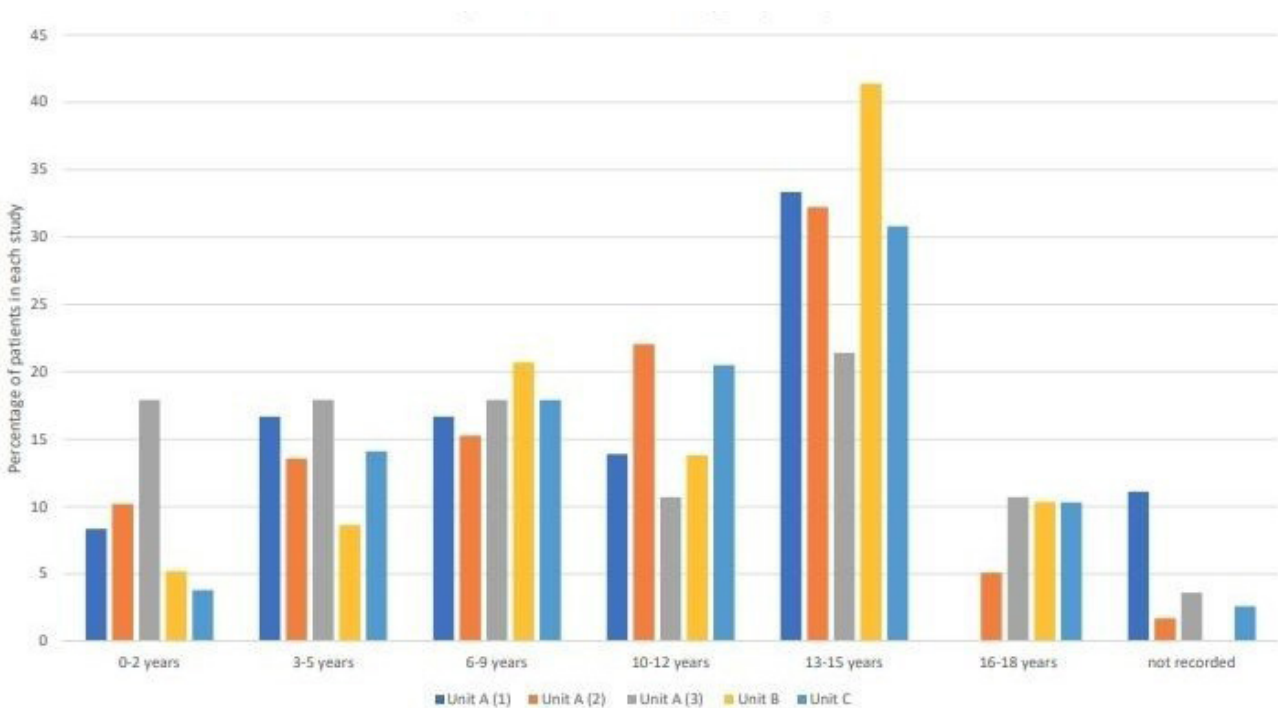


Figure 1 Distribution of age by study.

postendoscopy using a structured questionnaire. This study revealed areas within preprocedural and post-procedural parental communications that required improvement, as well as a need for standardisation of postendoscopy follow-up procedures.⁸

How this questionnaire aided local service change/improvement

All three units have found the questionnaire beneficial in understanding the patient and carer experience during endoscopy, particularly from free text feedback. Positive feedback was given for most aspects of endoscopy delivery, which was encouraging for all units involved. Unit A also found that repeated questionnaire use in the same centre aided quality improvement over time, which was reflected by an increase in overall patient satisfaction scores.

Box 1 : Selected free text feedback from all six studies

- ▶ 'The waiting room could have benefited from more books/magazines/activities for older children'.
- ▶ 'It was a long day would have been nice to be informed of how long we should be waiting'.
- ▶ 'Would have been helpful to have had leaflet in advance, about what to bring to TAU - dressing gown, slippers etc'.
- ▶ 'We felt uncomfortable when a different adolescent met with the anaesthetist and personal information discussed with him in the adolescent lounge'.
- ▶ 'Would like to have a map with canteen, coffee shop'.

Feedback from patients and carers at units A and B have identified the need for procedure-specific leaflets to improve patient preparation. Unit A has since developed and is now routinely providing leaflets for all GI endoscopic procedures, and since then the overall preprocedural preparation scores have improved. Communication regarding postprocedure follow-up was also identified by unit A as requiring improvement. Since then, unit A is developing specific leaflets highlighting postendoscopy care advice, and in the meantime, unit A-4 has shown that the number of families aware of their follow-up arrangements has also increased.

Free text feedback at unit A has identified the need for a specific adolescent space for preprocedure discussions, more activities for adolescents in the waiting area and more hospital car parking facilities, all of which have been addressed in the new hospital build.

The questionnaire results have prompted unit B to change practice by increasingly administering bowel preparation at home to older children instead of admission to the hospital the night prior to endoscopy. They also reflected on the need to improve patient preparation prior to endoscopy, including communication of the procedure as well as managing patient expectation of waiting times. At unit C, the questionnaire identified more patients reporting postendoscopy pain than expected, despite consistent use of pain scores, preoperative topical anaesthetic and paracetamol. As a result, unit C is undergoing a more detailed audit on postendoscopy pain management.

Observations during data collection: age of service users

There were relatively more responses from the 13–15 year age group compared with the 3–5, 6–9 and 10–12 year age groups across all studies (excluding unit A-4). This may reflect the natural epidemiology of GI diseases, which require endoscopy investigation. Unit C also had an older adolescent patient cohort with complex comorbidities such as neurological conditions. This was due to unit C's adult service not routinely offering endoscopy under general anaesthetic, and these occurred in the paediatric endoscopy list. This broad age range of service users highlight the challenge of designing a questionnaire that can assess the service as both child and adolescent centred.

Limitations

It has been well documented that a major limitation of using patient experience questionnaires to evaluate a health service is being unable to overcome selection bias, particularly when the completion of the questionnaire is not compulsory.⁹ The questionnaires in this study were all written questionnaires and were only provided in English, thus patients/carers in whom English was not the first language, or those with learning or reading difficulties, may find it difficult to express their views.

Results showed that the number of questionnaire respondents represented an average of 37% of the total number of endoscopies performed during survey periods. The limited response rates are a potential source of bias and require careful consideration to help improve future survey response rates. The smaller response rates in unit A-4 compared with other studies in unit A may influence data interpretation while comparing between studies to review service improvement. Variable completion rates to certain questions were also noted.

Reasons behind the limited response rates could include the following: most units asked patients and carers to complete the questionnaire immediately before and after their endoscopy, which could have been affected by issues such as preprocedure anxiety or recovery from anaesthetic. Some questions also asked about initial consenting and explanation of the procedure, which may have happened weeks prior to the endoscopy, and families may not remember this well enough to give a response, although consent and explanation would have been revisited just prior to endoscopy as part of a two-stage consent process. Unit A found that designating a specific individual to distribute and collect questionnaires (who was otherwise uninvolved in the patient's care) was helpful in increasing response rates.

Patient satisfaction questionnaires with mostly yes/no questions can also reduce a variety of patient responses compared with free text.^{7 9} A mix of yes/no questions and free text was used in this questionnaire. Unit C found more patients than the expected

reported postprocedural pain, but no further details were provided as this question only allowed for yes/no answers. Unit A found some respondents reported postprocedural bleeding and vomiting but this was likely to be mild, as concurrent audits did not reflect this as a reason for prolonged admission (data not shown). It is vital for local teams to note the importance of additional alternative sources of patient feedback such as encouraging free text comments and input from parent/carer forums, to gain a better insight into the patients'/carers' perspective.

Expectations and perspectives can vary widely between patients and their carers; therefore, it would be useful for local services to explore and accommodate both groups. Questionnaires used by units A and B did not address who completed the questionnaire, whether it was the patient, the carer or both. Although unit C did address this, only 10% were filled in by the patient themselves. Further work is needed to explore how the questionnaire could reflect both the patients' and their carers' views.

Suggestions for improvement include having separate questionnaires for patients and their carers, incorporating the questionnaires onto electronic devices such as tablets with a friendly, age appropriate user interface in order to increase response rates, offering voice recording as an alternative to writing free text, as well as giving the option of sending questionnaires out to patients and carers a few weeks postprocedure so that they can have time to reflect over their experience. However, a disadvantage would be that postal questionnaires may not improve response rates and can be more time-consuming and costly to undertake. Based on the three units' experiences, an exemplar questionnaire is attached in online supplementary appendix 1.

Importance of adapting the questionnaire to reflect on local service need

While units A and B used the same questionnaire in their studies, unit C adapted this to reflect certain aspects of its service which were unique to the unit (unit C questionnaire available on request) as detailed in the Methods section. The information obtained was thus tailored to their local service.

CONCLUSION

As an increasing number of paediatric endoscopy units will be completing the P-GRS as part of a national quality improvement initiative, they will need to attain insights into the patient and carer experience and perspective. Our questionnaire has helped each of the three units capture this and comply with some of the measures in the quality of patient experience domain of the P-GRS. It is hoped that a local modification of the current questionnaire could be used by units across the UK as part of their annual survey of their patient endoscopy experience, which will allow them to meet

the required measures in P-GRS and, more importantly, to ensure that patient and carer experience help drive any changes needed in their local processes.

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Contributors The study was planned by PN. PN and EG designed the initial questionnaire, which has been refined and condensed with subsequent use. EG conducted studies A-1 and A-2; JWYW conducted study A-3; and RR and ZZ conducted study A-4, all under the supervision of PN at Sheffield Childrens Hospital. ZL conducted study B at the Royal London Hospital under the supervision of DR. JM and AE conducted study C at Royal Stoke University Hospital under the supervision of AP. JWYW collated all datasets from coauthors. JWYW wrote and submitted the article with PN's supervision. MT provided critical review of the article.

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Competing interests None declared.

Patient consent for publication Not required.

Ethics approval Each unit secured approval from their local clinical governance committees before data collection. This project did not require ethics committee approval as this was a service evaluation questionnaire and the local governance committee mandates approval of all patient questionnaire surveys by Patient Advice and Liaison Service.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement All data relevant to the study are included in the article or uploaded as supplementary information. Data and individual questionnaires used in each study may be obtained upon request.

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