British Society of Gastroenterology position statement on patient experience of GI endoscopy

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Abstract

This position statement provides a framework on patient experience of gastrointestinal endoscopy, with recommendations and suggestions for practice to ensure high quality patient experience. This area is not previously covered by British Society of Gastroenterology (BSG) guidelines or position statements and is an important addition to this field.

The National Institute of Health and Care Excellence compliant BSG guideline development process was used throughout. A metanarrative review of the literature (systematic review plus qualitative data) on patient experience of GI endoscopy was performed and was used as the basis for development of statements by the writing subgroup of the Guideline Development Group (GDG). Proposed statements were evaluated by each member of the GDG (consisting of patient representatives, gastroenterologists, surgeons, a nurse endoscopist, an endoscopy nurse, a health psychologist and a public health research officer) on a scale from 1 (strongly disagree) to 5 (strongly agree) with 80% agreement required for consensus to be reached. Where consensus was not reached, a Modified Delphi process was used to re-evaluate and modify statements until consensus was reached or the statement discarded.

Finalised Statements and evidence quality were evaluated at a GDG round table meeting. The GRADE tool was used to assess strength of recommendations and evidence. 50 statements are included, covering 10 key domains, including definitions and terms, patient experience key principles, how and what information is offered to patients, how experience is measured, options available to improve patient experience, sedation practice, pre-assessment, endoscopy under difficult or complex circumstances, and departmental elements.

Introduction

The three dimensions of healthcare quality are patient safety, clinical effectiveness and patient experience. Much of healthcare practice tends to focus on the first two dimensions, however greater emphasis is now being given to the patient experience dimension.[1] The United Kingdom Francis Report[2] into a failing UK hospital suggested that statistics and reports had been preferred to patient experience data, and that losing sight of patients in this way had been detrimental to their care. The UK Darzi Report[3] into NHS practice suggested that measuring patient experience would highlight where improvements in quality of care could be made. In the United States, it is increasingly recognised that patients use measures of experience (such as the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) survey)[4] to evaluate healthcare providers, and that positive patient experience is associated with better patient outcomes.[5]

Clinical standards and safety in endoscopy are well reported and reviewed in the UK, via the Joint Advisory Group on GI Endoscopy (JAG) accreditation programme. The Global Rating Scale[6] used in JAG assessments includes a domain covering patient experience, but there is limited guidance available on how patient experience should be measured, or what standards should be achieved.

An executive summary of the statements can be found in Box 1 (supplementary material).

Aims

This British Society of Gastroenterology (BSG) position statement aims to provide a framework for units to assess, improve and monitor the experience delivered to patients undergoing gastrointestinal endoscopy.

Methods

Metanarrative review of the literature

A metanarrative literature (systematic review incorporating qualitative data) review was performed by the lead authors prior to establishment of this group. [7] The evidence from this review was used as the basis for developing the statements. The metanarrative methodology, along with the details of search terms and results are detailed in the published review and are not repeated here.[7] A metanarrative search was chosen rather than a traditional systematic review, as this methodology allows capture of all non-quantitative as well as quantitative data, as patient experience tends to be examined using predominantly qualitative methods. The same search terms used in the metanarrative review were re-run from 2014 to 2016 to identify papers published after publication of the metanarrative review.

Guideline development group and writing group formation

A guideline development group (GDG) was formed in accordance with the British Society of Gastroenterology NICE-compliant guideline process. This group was commissioned by the BSG Endoscopy Committee and consisted of eight gastroenterologists, a nurse endoscopist, one colorectal and one upper gastrointestinal surgeon, an endoscopy nurse, a health psychologist, a public health research officer and two patient representatives to ensure expertise across all the required domains. Two patient representatives (who both had experience of undergoing several endoscopic procedures) were selected for the GDG, and other group members were selected in part due to extensive previous work done working directly with patients about their experience, to ensure that the patient voice was heard during this project. The group developed the key areas for consideration in this position statement via email correspondence.

From within the GDG, a writing group was formed to identify the key search terms and develop the draft statements. The writing group consisted of three gastroenterologists, a health psychologist, a public health officer, and an endoscopy nurse. Two members of the writing group worked previously on the metanarrative review of the literature.[7]

Statement development

10 key domains were identified (see Box 2, supplemental material).

Draft statements within each key domain were formulated by the writing group based on literature available. Two rounds of formal anonymous voting were undertaken using online surveys, with a modified Delphi process conducted.[8] Each statement was reviewed by each member of the GDG and scored using a five-point scale (strongly agree, agree, neither agree nor disagree, disagree, strongly disagree), with comments invited on each statement. After round one, revisions to statements were made, with no removal of statements. After round two, those statements with ≥80% agreement (i.e. scored as 'agree' or 'strongly agree' by more than 80% of the GDG) were included in the position statement. Those statements with an agreement score of <80% were brought forward to a round table meeting at the BSG offices on 2nd March 2016 for further discussion, and a final vote (with anonymity maintained using electronic keypad voting). Those statements where agreement was not reached after these three rounds were discarded. Figure 1 (supplemental material) illustrates the results of the voting rounds. The final statements are presented here, with an indication of the strength of the recommendation (given as a percentage, that being the percentage of the GDG that voted either "agree" or "strongly agree") and the strength of the evidence to support each statement made using the GRADE scale.[9] The completed document has been peer reviewed by the BSG Clinical Services and Standards Committee in order to provide an external opinion on the statement produced.

Results

1. What are the key definitions and terms associated with patient experience of GI endoscopy?

a. We define patient experience as "feedback from patients on what actually happened in the course of receiving care or treatment" and reflect 'what' the patients experienced when they received care or treatment and 'how' that made them feel.

There is no widely accepted definition of patient experience – this definition is taken in part from the UK Doctor Foster 2010 report, "The Intelligent Board 2010 – Patient Experience,"[1] and in part from the UK National Quality Board 2015 report "Improving experiences of care: our shared understanding and ambition".[10] How patient experience is defined will impact on how it is measured.[11] Also, the way we ask patients to describe and report their experience will affect the results we achieve – for example; asking to rate satisfaction will garner different responses to asking about their observations and feelings about their experience.[10] As such, we acknowledge that feedback and experience are not one and the same, and that patients have had an experience of healthcare regardless of whether they have given feedback on it.

Strong recommendation, moderate quality evidence. 81.25% agreement.

b. We define gastrointestinal endoscopy as any procedure performed within a dedicated endoscopy unit, or by an endoscopy team, where an endoscopic device is used to assess or treat the gastrointestinal tract.

Within this definition, we also include:

i. The pre-procedure period includes: clinic consultations, the endoscopy booking process, pre-assessment (where utilised), patient's review of written patient information and consent documentation, preparation required (e.g. bowel cleansing preparation), access to the hospital and unit.

The treatment pathway starts for the patient at the point of referral, and as a feeling of ownership and involvement in their care is crucial to their experience of the health care service, we feel the steps prior to attending for an endoscopic procedure should also be

considered when reviewing patient experience. The patient experience may occur outside of a dedicated endoscopy unit, such as in a radiology unit or theatre department; for this definition we include any procedure performed by an endoscopy team, regardless of the location. Clinic consultations should be included within this definition if they were with an endoscopist; if, however the patient was referred for endoscopy from a non-specialist (e.g. GP direct access or referral from other hospital specialty) then this would not be included.

Strong recommendation, moderate quality evidence. 100% agreement.

ii. The procedure should involve experience on the day of the test up to and including the procedure itself and should include experience from the time of arrival in the department and time in the procedure room. This should also include interaction with staff.

This will most likely form the bulk of the patient experience. In previous years understanding of experience has focused primarily on patient comfort levels, gagging and embarrassment (depending on the procedure), but it is increasingly recognised that there are far more elements that make up the patient experience, including (but not limited to) communication, privacy and dignity, as well as comfort.[7]

Strong recommendation, moderate quality evidence. 93.75% agreement.

iii. The post-procedure period includes: immediate post-procedure recovery (and any impact that may have such as restrictions on driving or employment or observation period required), provision of results post-procedure, any considerations made for communicating results to those who have received sedative medication, and clinical follow up including initiation of management plans for any endoscopic diagnoses if appropriate.

Post procedure will include time in the recovery area of the endoscopy unit, the interactions with staff on discharge, communication of results from that day, explanations about restrictions during recovery (such as driving restrictions, the restriction on signing of legal documents, the need for supervision etc.), a plan for communication of future results (for example, histology results) and plans for future follow up. If a definitive diagnosis is made, then this post-procedure period will also include communication about treatment being started (for example, if peptic ulceration

is diagnosed and anti-acid medications started). It is acknowledged that in some cases, no diagnosis may be made and follow up with an appropriate team member may be required (for example, a normal colonoscopy in a patient with probable IBS symptoms).

Strong recommendation, moderate quality evidence. 93.75% agreement.

These 3 time periods reflect the entirety of the endoscopy process experienced by patients. Simply reporting the experience of the procedure does not provide a full picture of the experience. It has been shown that patients most highly rank interaction with the endoscopist and time to talk about the procedure before and afterwards,[12] demonstrating that there is more to the endoscopy experience than the procedure alone.

c. Patient reported outcomes (PRO) are defined as reports coming directly from patients about how they feel or function in relation to a health condition or its therapy.

The focus of this position statement will be on patient experience, and how it is measured. However, this definition[13] is included in order to highlight the difference between a PREM (Patient Reported Experience Measure) and a PROM (a measure of a PRO) as these are sometimes incorrectly used interchangeably. PROMs are standardised validated instruments (question sets) to measure patients' perceptions of their health status (impairment), their functional status (disability) and their health-related quality of life (well-being).

Weak recommendation, moderate quality evidence. 87.5% agreement.

d. Patient reported experience measures (PREMs) are standardised validated instruments (question sets) designed to measure patients' perceptions and views of their care or treatment and their interactions with health professionals and the health service.

PREMS are different to PROMS as they report the experience rather than the outcome from the patient point of view. They include all ways of evaluating the patient experience, including written or telephone surveys.[11]

For example:

The Oxford Hip Score is a patient reported outcome measure (PROM), where 12 questions are answered by patients about hip pain and function in relation to hip replacement surgery.[14] PROMs specifically to gastroenterology are detailed in a 2014 review article.[15]

PREMs focus on the experience of health, illness, or care interventions and might include scales such as the SF-36 and the EQ-5D scores. An example specific to endoscopy is the Colonoscopy Embarrassment Scale.[16]

Strong recommendation, moderate quality evidence. 100% agreement.

2. What are the key principles for optimising patient experience?

Published work on patient preferences demonstrate how patients prioritise various aspects of the endoscopy experience.[12] This work considers all aspects of the patient experience. Evidence suggests patients have a desire to have the procedure fully explained to them, along with the rationale for doing the test, and to have results explained to them in a timely fashion after the procedure.[17] These findings are borne out in prioritisation surveys.[12 18]

a. Patients should be fully involved (when capacity allows this) in the decision-making process when endoscopic tests or interventions are being considered.

The UK NHS Constitution states that, where appropriate, patients should be involved in all decisions about their care and treatment.[19] It has been shown that patients are more likely to attend for a procedure if they understand why it is being performed[20] and what it will entail.[21] They should also be made aware of any alternative method of investigating their symptoms, and a discussion should take place regarding risks and benefits. Patient needs and expectations should be kept in mind and addressed where possible. It has been reported that endoscopists underestimate the value of clear communication and shared decision making.[22] The National Quality Board indicate strong links between being involved in the decision-making process and improved safety and better clinical outcomes.[10]

Strong recommendation, moderate quality evidence. 100% agreement.

b. High-quality written information regarding the procedure, which is understandable to the patient, should be available to the patient to read (in their own time if they so wish) and adequate time should be available for discussion about the procedure and the anticipated experience with opportunity for repeated discussion if required.

The basic principles of informed consent state that patients must have received sufficient information to understand the procedure, its benefits and the potential risks.[23] This should be available to the patient in a timely fashion – ideally at the time of discussion about the intervention or sent out to the patient once the appointment is

booked. If information is provided in advance to the patient, they can decide about whether they read this documentation.

It has also been shown that when patients are provided with information about what to expect when they attend the hospital in advance of their appointment, attendance rates are better.[21] Patients also consider the written explanation about the procedure to be more important than nurses or clinicians do.[24] It should be made clear however, that written information should not replace one-to-one discussion, but be an adjunct to it.

Strong recommendation, moderate quality evidence. 100% agreement.

c. Adequate time and information should be available for discussion about the procedure and the anticipated experience for the patient, with opportunity for further discussion if required.

Patients should feel able to ask questions. Meeting patient expectations before an intervention is associated with improved treatment compliance[25] and conversely not addressing expectations is associated with reduced satisfaction with healthcare.[26] The UK NHS Department of Health suggest patients should be involved in decision making as part of "no decision about me without me",[27] and this will require the opportunity for patients to discuss their treatments in detail if needed. It has been found that patients attending open access flexible sigmoidoscopy procedures were less satisfied with their procedure than those undergoing an identical procedure who had been seen first in an outpatient clinic setting with explanation of the procedure in advance.[28] When discussions about the procedures occur in advance of attending for the procedure systems should be in place to allow further discussion if needed. Patients may develop concerns or worries in the interim after a clinic consultation for example and should have contact details should they wish to re-discuss the procedure.

Strong recommendation, moderate quality evidence. 93.75% agreement.

d. A discussion regarding the proposed procedure should occur (with the necessary caveat of emergency or life-threatening event and following guidance for patients lacking capacity) with an individual who understands the procedure. Ideally this should be the person performing the procedure. However, it does not have to be an individual who will or can perform the procedure but should be someone trained to discuss it. The discussion should allow time for the patient to ask questions and have them answered in a way that is understandable to them.

Informed consent is crucial to ensure that procedures are being carried out appropriately and with the understanding of the patient, and without breaching the human rights of the patient. BSG guidelines on consent in endoscopy were published in 2008[29]. Information and consent forms one of the standards within the endoscopy Global Rating Score.[6]

Ideally the person performing a procedure should seek the patient's consent. However it can be obtained by another person on behalf of the treating practitioner if that person is able to perform the procedure or has been specifically trained to seek consent for that procedure.[23] BSG guidance suggests that endoscopy nurses can be trained to seek consent, locally assessed and accredited and record this training in their portfolio. This should be updated and reassessed regularly.[29] In the event of consent being taken by someone other than the endoscopist performing the procedure efforts by the endoscopist should be made to countersign the consent and engage in interaction with the patient once in the procedure room in order to foster a positive relationship.

Strong recommendation, low quality evidence. 100% agreement.

e. On attending the endoscopy unit, there should be an opportunity to speak with an individual (this may be a clinician, nurse, or individual with understanding of the procedure) before and after the procedure.

When prioritising aspects of the endoscopy experience in terms of their satisfaction, explanation of the procedure and answering of questions was more important to patients than noise levels, privacy and waiting time prior to the procedure.[18] Patients in another series had no preference between endoscopist or nurse when discussing

what the procedure would entail but preferred to discuss results with the endoscopist who performed the procedure.[12]

Strong recommendation, moderate quality evidence. 100% agreement.

f. The person performing the procedure (or supervising a trainee performing the procedure) should be technically skilled at the procedure, and able to communicate clearly with the patient.

Patients rank this highly.[12 18] They may not necessarily know how to tell if someone is skilled but may base their view on the communication skills they encounter. Endoscopy departments should ensure high quality procedural skills and monitor this through review of key performance indicators, departmental audit, review of performance and training. Unit JAG accreditation will address this, along with ensuring that all endoscopists are JAG accredited and trained.[30] Where a trainee is performing the procedure the supervising clinician should be present at all times according to agreed rules and communication with the patient should be maintained to ensure optimal patient experience.

Strong recommendation, low quality evidence. 93.75% agreement.

g. All staff (endoscopists, nurses, allied health professionals, and non-clinical staff) at the endoscopy unit should be courteous, respectful, sensitive and friendly.

Patients rank the personal manner of the endoscopy staff highly when reflecting on satisfaction.[18] The Francis report suggested that taking focus away from the patient experience is detrimental to their care.[2] The NHS Constitution states that patients should be treated with respect, dignity, compassion and care, and also that staff should be treated in the same way, an acknowledgement that a two-way relationship is needed to facilitate a positive experience.[19]

Strong recommendation, low quality evidence. 100% agreement.

h. Discomfort, pain, and embarrassment during the procedure should be controlled and kept to a minimum.

There is a large amount of work on different endoscopic methods and almost all studies include a measure of comfort, usually as a secondary outcome. The patient experience is multifactorial, so focus should not be purely on sedation and analgesia practices.[11] However, adequate control of discomfort is highly ranked by patients,[18] and therefore should be given due consideration – the patient's wish for a level of sedation that differs from the endoscopist's preference should be considered but safety must be maintained. It is usually measuring using visual analogue scales or numerical rating scales and is frequently clinician assessed[7] despite discrepancies between patient reporting of discomfort compared to nurse or endoscopist reporting. As well as measuring patient comfort, when discomfort is reported it should be responded to appropriately.

Strong recommendation, moderate quality evidence. 100% agreement.

3. What are the key principles in assessment of patient experience of GI endoscopy?

Almost all measures of patient experience to date are derived from clinician opinion on aspects of procedures that they feel are important to patients rather than derived from patients directly.[7] An ideal tool should be patient derived and validated for use in an endoscopy setting. Only one specific validated tool for endoscopy experience assessment exists [31] but this was not patient derived.

a. Patients should be encouraged to give real-time feedback on their experience (for example discomfort, embarrassment, pain etc.) during procedures where possible so that measures can be taken to adjust this.

Levels of discomfort and embarrassment vary throughout a procedure. A real-time measure will allow adjustments in practice to improve the experience for the rest of the procedure. This may only be possible during some procedures; for example, verbal feedback during upper gastrointestinal tract endoscopies will not be feasible. Each case should be considered individually, and a decision made regarding how/when/if feedback should be communicated – in particular, consideration should be given to how feedback is obtained from those who receive heavy sedation. Where feedback is feasible during the procedure it should be immediately available to the endoscopy team so that changes can be made as required. Feedback from patients will provide a more accurate assessment of their comfort – it has been shown that nurse or clinician assessment of patient comfort does not correlate well with what patients themselves report.[32-35] This feedback should also be collated and fed back to the endoscopy department as a whole and clinicians individually in order to maintain or improve practice.

Strong recommendation, moderate quality evidence. 93.75% agreement.

b. Measures to assess patient experience should be patient derived. They should be developed using robust psychometric methodology (i.e. the components assessed should reflect the direct reports of patients who have previously undergone the procedure, rather than derived from clinician opinion).

To date, almost all measures of patient experience are derived from clinician opinion and literature review rather than derived directly from patient reports of endoscopy experience, and these differ.[7] Qualitative work suggests that although some tools (such as the UK Endoscopy Global Rating Scale (GRS)) do address many of the aspects that patients find important,[36] further work is needed to fully explore the patient experience in order to accurately measure it. Any measures developed should be done so using psychometric methodology and be subjected to validation, reliability and responsiveness testing.[37]

Strong recommendation, low quality evidence. 87.5% agreement.

c. Patient experience measures should be appropriately and scientifically validated before use.

Validation of a measure ensures that it can reliably measure what it purports to measure, and has construct, content and criterion validation.[37] Measures should also be tested for reliability and responsiveness. Only one validated tool specific to GI endoscopy exists.[31] Other measures for generic assessment (for example, the Short Form (36) Health Survey, the Hospital Anxiety and Depression Scale, etc.) are validated but not specific to GI endoscopic practice. Pain scores are frequently used, but again not validated for this setting. In the absence of more than one validated tool (and none that are patient-derived), subjective measures and non-validated tools do hold value, as they will raise awareness of the measurement of patient experience amongst healthcare professionals.

Strong recommendation, low quality evidence. 93.75% agreement.

d. Patient experience tools should assess the broad range of elements that affect patient experience (including (but not limited to) pain, gagging and embarrassment levels but also including elements such as interaction with staff, practicalities within the unit, pre- and post-procedure processes and information provision).

Qualitative work with patients demonstrates that their experience of GI endoscopy is formed by far more than purely pain/gagging levels or direct physical discomfort. A comprehensive assessment of the patient experience will need to cover a wider range of aspects of endoscopy, based on what patients value and prioritise.[38] The NHS Patient Experience Framework[39] identified important areas to consider which are further expanded by the National Quality Board,[10] and an approach to these is discussed in The Health Foundation document.[11]

Strong recommendation, moderate quality evidence. 93.75% agreement.

4. What options (that may alter patient experience of GI endoscopy) should be available?

For example, what choices are offered – choice about the test to be performed, choice of location for test, choice of endoscopists, timing of procedures, sedation options, method of transfer of information pre and post procedure, etc.

a. Patients should be made aware of all the locations where the required test can be performed by the providing institution.

Where more than one option is available, patients should have a choice regarding where their procedure takes place. A choice of location is important to some patients and they may be prepared to wait longer to have an appointment at a unit which has a stronger reputation or is more conveniently located.[40] Reasons for a particular preference of site may also be personal to the patient, such as previous experience of family members. Options available to the patient may either be in terms of overall provider (for example when an initial primary care referral is being made) or where services are provided within a hospital trust but should always be at accredited endoscopy institutions. Details of each location should include an indication of which practitioners work there and advise on any potential limitations to provision of the procedure (for example, options for sedation) or the patient environment (for example whether same sex lists are available; although this cannot be offered as standard, single sex accommodation should always be provided).

Strong recommendation, low quality evidence. 93.75% agreement.

b. Patients should be able to select a time (within reason and the practical constraints of service delivery) that suits them for their test to be performed. A range of feasible times should be available. Consideration should be given to offering appointment times outside of traditional working hours.

Patient selection of appointment time is associated with a reduction in non-attendance rates and enhances the experience of the process.[41] This may not be appropriate for procedures where a limited number of practitioners can perform the procedure or specific procedure requirements (such as rooms, equipment, staff) are required.

Offering a range of available times and allowing patients to change these appointments to suit their wishes may be the most appropriate way to allow flexibility for patients.

Much work has been done on timings of patient appointments. There are conflicting data; a study of rheumatology outpatient appointments suggested only 2% of patients wanted an out-of-hours appointment,[42] compared to a review of cardiac and respiratory clinic patients where 63% patients preferred an out-of-hours appointment.[43] Being employed did predict an out-of-hours preference [42] also seen in GP appointment preferences where choice of time was six times more important than a shorter waiting time.[44]. Services should be responsive to their local patient needs.

Weak recommendation, moderate quality evidence. 87.5% agreement.

c. Patients should be encouraged to make an informed decision regarding sedation and analgesia.

Provision of high-quality, balanced and evidence-based information regarding the procedure in advance (as previously outlined) should empower patients to decide on the method of sedation or analgesia they prefer in advance of their procedure. This should also include information regarding the time period following the procedure where they will be affected by sedative medication. In order to ensure all the necessary information is conveyed to the patient, information leaflets may include significant amounts of clinical information, however this should not replace a face-to-face discussion if needed. Both written and verbal information may be required to ensure the updated UK consent laws are addressed.[45] There should be a 'shared' decision made between the patient and the endoscopist and whilst a patient should have choices, those options should be safe and appropriate, such that the patient should not be pressurising the endoscopist into delivering an unsafe procedure.

Strong recommendation, low quality evidence. 93.75% agreement.

d. Patients should be given the opportunity to discuss the results of the procedure afterwards, with immediate results discussed and a clear plan made for how they will receive further results.

This is prioritised highly by patients[18] and ties in with promoting ownership of their healthcare. Feedback should ideally be offered in a private room[41] and where possible delivered by the endoscopist. In one series, 56.5% preferred to discuss results with the endoscopist, versus 2.3% with the nurse (41.2% had no preference).[18] Where sedation is given, a plan for follow up at a later time should also be made.

Strong recommendation, moderate quality evidence. 100% agreement.

e. Patients should be able to request an endoscopist of a particular gender. Where this is not possible adequate explanation should be provided.

Data from the Bowel Cancer Screening Programme shows that women have a much stronger preference for flexible sigmoidoscopy to be carried out by a female practitioner than men do.[46] Similar results were demonstrated in American colonoscopy studies.[47 48] Patients should be allowed to state a preference about the gender of their practitioner, but be aware that this may not be possible to accommodate; for example, due to potential delay to the procedure being performed, the expertise required to perform the procedure or other legitimate reasons. This information should be expressed in advance to the patient (for example, in the written information provided) so that patients are aware prior to the procedure.

Strong recommendation, moderate quality evidence. 100% agreement.

5. What information is given to patients before the procedure and how is it provided?

a. Patients should be offered high-quality, balanced and evidence-based written information regarding the procedure. They should also have the opportunity to discuss the procedure if they so wish (e.g. come to a clinic or have a phone conversation with a staff member rather than a direct-to-test pathway).

Adequate understanding of what the procedure involves has been shown to improve attendance rates,[41] reduce anxiety and improve overall patient experience of endoscopy.[49] As some patients prioritise the timing of the procedure, direct-to-test pathways are appropriate,[12 18] however it has been shown elsewhere that attendance rates may be better when the patient has been referred from a clinic[50] so this should remain an option for those who wish to see a clinician first. Telephone pre-assessment may offer an alternative option for some procedures and prevent delays whilst waiting for a clinic appointment. The information provided in advance of the procedure should be complete; one study suggested that despite an information sheet being sent out before a direct-access colonoscopy, patients felt some of the most useful information they received was from staff in the endoscopy unit on the day of the test (that is, after they had already been through the bowel preparation process.)[51] Information should be individualised for the procedure in question, and for the site offering the procedure.

Strong recommendation, moderate quality evidence. 93.75% agreement.

b. Patients should be given a clear indication of the benefits and risks of the procedure based on the best available evidence. Potential consequences if adverse events occur should be discussed.

Patients need to be fully informed about the procedure in order for consent to be valid.[23 29] It has been demonstrated that there is no difference in the level of understanding of the risks and benefits of a procedure when consented by an endoscopy nurse versus a clinician, but understanding should be checked before signing the consent form.[52] Information should be presented in a way that is understandable

to the patient. A survey in an outpatient and endoscopy unit of patients' opinions on important information to be given during consent demonstrated top scores equally to major complications, effect of not undergoing the procedure, effect on future management of the condition and long-term effect on work. Technical details of the procedure and minor complications were given less importance.[53] However, after the Montgomery ruling of 2015 (on a UK obstetric case where complications arose, and the complainant felt the consent process had not adequately covered all the possible complications), the information relayed during the consent procedure needs to be carefully considered, taking each case on an individual basis to establish what information that patient should be told.[45] Patients should also be made aware of who they can talk to should any complications arise as part of their procedure.[54]

Strong recommendation, moderate quality evidence. 93.75% agreement.

c. Information regarding the sedation and analgesia options for the procedure should be available to the patient and an opportunity to discuss these provided prior to the procedure.

Control of discomfort during procedures is ranked very highly by patients [55] and as such the decision about which sedation method to use should be a decision made with the patient. Documentation sent to patients in advance or discussions in clinic before referral to endoscopy should include information about the options available. Providing patients with details of the methods available and forming a "decision tree" to inform the method used has been shown to be useful.[56]. An explanation of the levels of sedation and the BSG guidelines on sedation doses may also be useful.

Strong recommendation, low quality evidence. 93.75% agreement.

d. Patient information should be available in different formats – for example in alternative languages written, online, audio recorded, Braille. These may be site specific or generic NHS information.

The UK Equality Act 2010 aims to reduce inequalities in care and eliminate discrimination.[57] To this end, no patient should be excluded from receiving care, and as such, information should be accessible to all patient, and is monitored by the UK Care Quality Commission.[58] A new UK Accessible Information Standard was agreed in June

2015 and must be followed by all NHS organisations by July 2016.[59] All information formats should be reviewed regularly, and have feedback mechanisms in place to assess their usefulness.

Strong recommendation, low quality evidence. 100% agreement.

e. Patients should have the opportunity to request a discussion about unit and endoscopist performance data prior to the procedure. It is essential that data are accurate, validated and presented in a way in which they can be fairly interpreted.

The technical skill of the endoscopist is perceived as the single most important factor affecting patients attitude to endoscopy .[12 55] Allowing patients to review unit and endoscopist data will allow them to consider this. Consultant outcome data for UK surgical specialties are now available online,[60] and reports such as those from Dr Foster allow patient access to performance data, although this tends to be limited to accreditation status and/or mortality figures. It should be ensured that the data presented is accurate and this reporting does not lead to alterations in selection for and reporting of procedures by clinicians or departments in order to falsely maintain standards.[61] The data should be presented in such a way that is understandable to patients and can be correctly interpreted, and does not encourage "gaming" by units or clinicians. [62-64] It may be appropriate for these data to be released via an independent body, such as JAG.

Strong recommendation, low quality evidence. 93% agreement.

6. How is information given to patients after the procedure?

a. The results of the procedure should be discussed with the patient.

An American study of patient priorities in endoscopy showed that a discussion after the procedure was ranked 7/15, higher than privacy, noise in the endoscopy room and waiting times.[55] Anxiety levels are shown to be lower in those who can recall the discussion after a procedure. These discussions should only take place if the setting and support for the patient is appropriate, for example support for those with learning

difficulties or dementia, or specialist support (such as nurse specialists) if a significant diagnosis (such as IBD or cancer) is made. Where a complete diagnosis cannot be made (such as when histology or cytology results are pending), then a plan for further follow up is also needed. In those that have received sedative medication, the discussion may need to be repeated once the sedative effect has abated, and careful consideration made for those in whom a cancer diagnosis has been made, with utilisation of specialist nurses or urgent follow up appointments. As with all information given to patients, it should be in a manner that is understandable to the patient. These conversations and provision of information should only be held if the patient wishes them to go ahead.

Weak recommendation, moderate quality evidence. 87.5% agreement.

b. Immediate post-procedure results may be discussed by nursing or appropriate staff if they have the skills and training to communicate those results.

One study suggested the majority of patients (56%) preferred to have results explained to them by the endoscopist but 40% had no preference who delivered the results.[12] This will depend on practicalities within a unit overall and within each endoscopy list. As with nurse-led consent, appropriate training should be offered to staff who will be conducting these discussions.

Strong recommendation, moderate quality evidence. 100% agreement.

c. Access to the clinician who performed the test, or a suitable deputy should be available before patients leave the department.

This is unlikely to be needed all the time, but should be an option should the patient wish; it has been shown that over half of patients would prefer this option for a discussion after the procedure, although they do not have the same preference for discussions prior to the procedure.[12] This may not be necessary if an adequate discussion has already taken place (such as those discussed in statement 6b). It should be noted that in some cases, the person performing the diagnostic test may not be best placed to have more detailed discussions about ongoing management; in these

situations, a clear plan for future consultations and follow up should be made before the patient leaves the department.

Strong recommendation, low quality evidence. 93% agreement.

d. A clear plan for follow up should be communicated with the patient.

A clear follow up plan should be explained to the patient both verbally and with a copy in writing, with details of who follow up will be with, and a timescale for that follow up. This plan should have been made by the referring clinician, although results of the procedure may require the endoscopist to alter this as appropriate. This plan should also be communicated to the patient's General Practitioner.

Weak recommendation, low quality evidence. 87.5% agreement.

e. An understandable written summary of the main findings should be provided to the patient.

A small American study demonstrated reduced post-procedure anxiety, improved recall of findings, and a possible increase in compliance if patients were provided with a written endoscopy report after the procedure.[65] This is also demonstrated in a further study where recall of recommendations was improved by providing a written report.[66] In both studies, the written report (simply a copy of the formal endoscopy report filed in the patient records) did not replace a verbal discussion of results. For complex procedures where reports contain significant amounts of medical jargon, a "patient-friendly" report may be required, or pre-prepared information sheets about various diagnoses may be beneficial. If not all information is immediately available (for example, where histology results are pending) this may not be practical, in which case a verbal explanation should be given, and a plan for follow up made.

Strong recommendation, low quality evidence. 93.75% agreement.

f. Alternative methods to communicate results are needed for some patients who have received sedative medication.

Medication such as midazolam and propofol used during endoscopy cause amnesic effects[67] which reduce recall of discussions post-procedure. A small study found that

a wrist band to prompt reading of instructions was not effective and that it was the follow up phone call where discussion about results and follow up plans that patients found most useful.[68] As anxiety levels are shown to be higher when understanding of the results is lower,[65] it would suggest that those who cannot remember any discussions will have higher anxiety levels as they await review. As previously discussed provision of written results improves recall and compliance with treatment and provides an aide memoir for those who have received sedation.[65 66]

Weak recommendation, low quality evidence. 81.25% agreement.

7. Sedation practice and safety

a. Patients should be given a choice of appropriate sedation regimen. This should be based on the risks and benefits of each method being presented to the patient in advance of the procedure.

The options available should be made known to the patient prior to attending for the procedure. This information could be transmitted to the patient by the clinician at the time of deciding to undertake the procedure, by pre-assessment staff, or in written format before the procedure. The options made available should be within the safety guidelines and practices employed by the endoscopy unit and each case should be considered on an individual basis with discussion with the endoscopist.

Discussions can be either in advance in clinic settings or prior to completion of consent and entry into the procedure room in the endoscopy department after the patient has been presented with documentation on the risks and benefits prior to the procedure. Verbal discussions should be with an individual able to give an accurate account of the risks and benefits of each method of sedation. It is acknowledged that provision of some requests (for example, general anaesthesia) may be difficult; this should not be excluded from the options for the patient, but an indication of limitations and impact on waiting time and other factors made clear to the patient.

Weak recommendation, low quality evidence. 81.25% agreement.

b. Patients should be offered the choice of unsedated or sedated colonoscopy and flexible sigmoidoscopy.

It has been shown that colonoscopy is as well tolerated sedated as unsedated in correctly selected and willing patients.[69-73] The option for either should therefore be presented to the patient; the clinician's preference should not take precedence. It should also be made clear to unsedated patients that they can change their mind during the procedure provided they were assessed as suitable for sedation prior to the test. One caveat to this statement is where services have been established with no facility for sedation for example the UK NHS Bowel Cancer Screening Programme only offer unsedated flexible sigmoidoscopy.

Weak recommendation, moderate quality evidence. 81.25% agreement.

c. Patients should be offered the choice of unsedated or sedated upper GI endoscopy.

Watson et al[35] demonstrate in a series of 100 patients attending for OGD that 55 opted for sedation and 45 for an unsedated procedure. 88% were subsequently willing to repeat the test under the same circumstances, with no difference between the two groups. Some work has been done on predicting factors that influence tolerance of the procedure,[74 75] and work has also been done comparing tolerance with differing diameter endoscopes[76-78] suggesting that thinner scopes are better tolerated and more likely to be tolerated in unsedated cases.

Weak recommendation, moderate quality evidence. 87.5% agreement.

d. Providers of ERCP and EUS services should be able to offer deep sedation or general anaesthetic for planned procedures.

A meta-analysis of propofol as a sedative agent demonstrated good safety, recovery, and patient tolerance profiles.[79] Given these demonstrated benefits, all units offering ERCP and EUS should be able to offer deep sedation, and have anaesthetic support as needed for these cases. In the cases of sites that are unable to offer these services, local networks and referral pathways should be in place to facilitate transfer of care to a site that is able to offer these services.

Weak recommendation, high quality evidence. 87% agreement.

e. A tool (such as, but not restricted to, the WHO checklist or similar) should be used as the patient enters the procedure room, in order to identify all personnel involved in the procedure, ensure details of the procedure are known, and that all specific issues addressed (such as sedation wishes).

The WHO checklist was introduced in order to improve outcomes in surgical procedures. It was trialled in 8 countries, and showed a significant reduction in death rates and post-operative complications, and is now commonly used across the world.[80] With increasing demand for endoscopy, and the ability to perform

increasingly advanced procedures,[81] endoscopy has many similarities with surgery, and should adopt similar methods for maintaining safety. A 'huddle' at the start of a list also allow the personnel in the list to meet and discuss their own level of skill and introduce themselves to each other. The checklist used should be adapted to be appropriate for use in an endoscopy unit, and consideration given to the best way to implement and evaluate such a tool.[82 83]

Strong recommendation, moderate quality evidence. 93.75% agreement.

8. Maintaining the best possible patient experience in complex or difficult situations (e.g. emergency procedures, complex procedures).

a. Where patients have capacity, they should be involved in decision making, even in urgent/emergency situations.

Consent should be informed wherever it is possible.[23 29] Full explanations to patient and relatives should be undertaken where appropriate. Ongoing discussions should occur during the procedure if possible/appropriate. Staff will need to have had adequate training to assess capacity in difficult circumstances. Communication with family (who may act as advocates for the patient if appropriate) will also need to be maintained.

Strong recommendation, low quality evidence. 93.75% agreement.

b. All treatment options, including endoscopic options should be discussed if the patient has capacity.

To ensure good informed consent, the risks and benefits of all available treatment options should be discussed if the situation allows. Next of kin may be able to provide advocacy if the patient lacks capacity, although if procedures are deemed life-saving it may not be appropriate to delay for this. Options for referral to other clinicians/centres should be made apparent if appropriate.

Strong recommendation, low quality evidence. 100% agreement.

9. Can pre-assessment help optimise the patient experience of GI endoscopy?

Pre-assessment has been utilised in the surgical world for some time, initially in response to the new deal for doctors which reduced working hours, with a resulting development in nursing roles to cover services such as the assessment required before surgery.[84] As well as making an assessment of patient suitability for procedures, and to communicate details of the risk and benefits, it also provides an opportunity to address issues that may influence patient experience.

a. Pre-assessment should be conducted by an individual able to explain the procedure, preparation, and follow up.

This can be either a medical staff member (doctor) or a member of nursing staff trained in pre-assessment and consent. It allows for detailed discussion about the planned procedure, as well as a discussion about the risks, benefits, and alternative. Staff delivering pre-assessment clinics should be appropriately trained to perform these tasks. It has been shown in the surgical field that there are fewer late cancellations[85] and few complications when pre-assessment is performed by nursing staff.[86]

Strong recommendation, moderate quality evidence. 100% agreement.

b. Pre-assessment allows time for dissemination of information about the procedure.

Information can be provided and discussed at the time of pre-assessment, with understanding then checked again when attending for the procedure. An NHS Improvement document suggests pre-assessment allows better understanding of the procedure,[41] which has been shown to have an associated improvement in attendance.[87] Information can be provided in several different ways, and has been shown to be effective at addressing patient questions and concerns – through provision of written leaflets,[52 88] face-to-face discussions, or more innovative methods such as providing videos.[32 89 90]

Strong recommendation, moderate quality evidence. 93.75% agreement.

c. Pre-assessment allows information to be given so that patients can make a decision regarding sedation regimen in an informed manner.

Patients can be provided with data on risks/benefits of the various sedation techniques available to them. Ideally, this information should be provided in written format in advance of the pre-assessment clinic, with a decision about sedation made at pre-assessment. If, however, pre-assessment occurs immediately after the decision to refer for the test (for example, in the clinic) then the information can be provided, and a final decision made about sedation later. If decisions are made in advance, the effect of anxiety on their decision-making at the time of the procedure is reduced.

Strong recommendation, low quality evidence. 93.75% agreement.

d. Pre-assessment allows patients time to ask questions and have them answered.

In a study where consent documentation and information sheets were shown to patients and lawyers who specialised in medico-legal cases, it was proposed that there should be around 2 weeks between receiving the information and completing consent, and more than one opportunity to discuss the procedure.[52] Whilst a time period as long as 2 weeks may not be needed, pre-assessment allows some time to ask questions and process the information being provided to be built into the endoscopy patient pathway. In those where consent is completed in advance of the procedure, a brief confirmation of consent should be completed by the endoscopist on attending the unit.

Strong recommendation, low quality evidence. 100% agreement.

e. Pre-assessment allows pre-procedure anxiety to be assessed and addressed.

Anxiety reduction is complex, but qualitative work has shown an improvement in anxiety when patients attend pre-assessment clinic (taken from orthopaedic practice).[91] This is transferrable to the endoscopy setting – one small study shows that even in inpatient cases, there is reduced anxiety, better tolerated procedures, and a reduction in sedation use when patients had been pre-assessed by an endoscopy nurse.[92] Identifying those with high levels of pre-procedure anxiety may allow

selection for sedation in order to improve tolerance.[74] Fewer slots are wasted through “did not attend” episodes if the patients go through a pre-assessment process first.[41]

Strong recommendation, moderate quality evidence. 93.75% agreement.

10. What aspects of departmental and endoscopist organisation and training are required in order to provide optimal patient experience?

a. Staff should be correctly trained to deliver safe and accurate endoscopic procedures, whilst maintaining a positive patient experience.

JAG accreditation standards ensure that a unit meets agreed levels on clinical quality, the quality of the patient experience, workforce, and training.[93] Keeping up to date with these domains should ensure a unit performs at the peak of its ability. On-going training of staff should be encouraged and clear guidelines and policies on practice will be key to delivering high quality services.

Strong recommendation, low quality evidence. 100% agreement.

b. Units should be staffed and stocked adequately in order that lists run smoothly and without unnecessary delays or changes.

The use of WHO checklists[83] will ensure that details of the procedures being performed are known, and equipment collected as needed to ensure smooth running of the list. Unit management and endoscopy user group meetings will ensure up to date information about equipment required, and current stock levels. A "huddle" at the start of each list or day will ensure all staff are introduced to each other, establish if the case mix is appropriate for the staff in the room and vice versa, and have been shown to improve staff awareness and help to reduce patient harm.[94]

Strong recommendation, low quality evidence. 100% agreement.

c. Interruptions to procedures and lists should be minimised in order to reduce distractions and stress for the patient, the endoscopist, and the staff in the room.

Distractions (such as noise, conversations, additional tasks to the procedure in hand) in the surgical setting have been shown to prolong the time taken for procedures to be performed, with an associated deterioration in the quality of performance in less experienced practitioners (but no loss of quality in more experienced

practitioners).[95] Allowing a list to run as smoothly as possible may also reduce drop off in performance towards the end of the session – it has been demonstrated that ADR declines towards the end of a list, despite other endoscopic factors (length of procedure, depth of insertion etc.) remaining constant.[96]

Strong recommendation, low quality evidence. 100% agreement.

d. The patient should remain the focus of attention when in the procedure room.

The personal manner of the endoscopist, and the nursing and support staff are important to the patient.[18] This interaction should continue during the procedure. Feedback from the patient during the procedure will allow adjustments to be made to ensure the experience is as good as possible, and some assessment tools developed allow for several episodes of patient feedback.[31] Qualitative research has also shown that patients pick up on extra noise in the room, as well as the presence of unnecessary people,[17] all of which may impact negatively on their overall experience. As the focus should be on the patient, there should be an aspiration to streamline nursing duties and paperwork to allow this focus.

Strong recommendation, low quality evidence. 100% agreement.

e. Feedback on patient experience should be available to individual endoscopists and to the staff body at departmental meetings in order to guide future changes to practice or highlight current good practice.

Feedback to endoscopists on procedural quality indicators (such as caecal intubation rates, adenoma detection rates, etc.) leads to improvements in performance.[97] Studies have also included patient satisfaction scores in this feedback, although there did not appear to be an impact on these scores after feedback.[98] However, drawing attention to good practice, and allowing other endoscopists within a unit to see how they compare will foster an environment where positive change can be made.

Strong recommendation, low quality evidence. 93.75% agreement.

Statements not included

Over the course of the voting rounds, 4 draft statements were merged into other statements. 4 draft statements did not have consensus reached and were therefore not included in the final document.

Three of these statements focused on the provision of deep sedation for endoscopic procedures (one statement for each of lower GI endoscopy, upper GI endoscopy, and ERCP/EUS). The GDG felt quite strongly that there is evidence to support the use of deep sedation (i.e. propofol) for ERCP and EUS. A meta-analysis of propofol as a sedative agent demonstrated good safety, recovery, and patient tolerance profiles,[79] and is frequently used worldwide. A UK ERCP benchmarking project demonstrated only 3% of ERCP were performed under propofol or general anaesthetic in 2012.[99] Previous audit of ERCP practice suggested that in cases where conscious sedation was used, one third received doses of midazolam greater than 5mg,[100] despite guidelines suggesting no more than 5mg should be used.[101] The GDG felt that all units should be able to access deep sedation or anaesthesia for ERCP and EUS (as per statement 7d) but currently this option could not be offered routinely to patients, as making such a recommendation would currently be unachievable for most units. This reflects current service provision, and the current UK recommendation that deep sedation should only be administered by an anaesthetist. It was felt that the evidence for deep sedation in colonoscopy and upper GI endoscopy was less compelling with a meta-analysis suggesting that propofol did not provide better sedative effect than traditional sedation techniques, but safety was maintained..[79] Use of deep sedation for prolonged colonoscopic procedures, such as for large endoscopic mucosal resections of endoscopic submucosal dissections may also need to be considered separately to standard colonoscopy.[102] As purpose of this position statement is to optimise patient experience, but without recommending provision of a service that is currently not possible to deliver, all recommendations about deep sedation were removed. The GDG feel this is an area where recommendations may change in the future, and certainly in the case of ERCP and EUS, there should be a drive to offer deep sedation routinely.

A final statement explored the use of transnasal or ultrathin upper GI endoscopy. A recent UK review of transnasal endoscopy (TNE) suggests it is increasingly available,

well tolerated, and with good safety profile due both to the lack of sedation required and the reduced sympathetic stimulation and subsequent lower cardiovascular stress.[103] Yield of TNE has been shown to be similar to standard endoscopy for Barrett's oesophagus and early gastric and oesophageal lesions, although there is some conflicting data on early gastric cancer lesions.[103] It was felt by the GDG that despite the superior comfort and tolerability, the concerns with regards to imaging quality and diagnostic accuracy were too great to include this currently. It was also felt that provision of these services might be beyond the capacity of many units. However, the GDG felt this area, and indeed any new developments in all endoscopic equipment, should be kept in mind when this position statement is reviewed in the future.

Discussion

GI endoscopy is widely performed with around 1.7 million procedures performed in the United Kingdom each year. Measurement of patient experience is poorly defined and inconsistently applied. This position statement seeks to provide a structured approach to measuring patient experience. Patient experience is multifactorial and can be affected by many elements of endoscopic procedures. This statement provides a framework for endoscopy departments to ensure a positive patient experience is delivered moving beyond the rather poor measures of simple comfort scores or satisfaction surveys. Implementation of these recommendations and suggestions should be achievable for endoscopy units, without significant cost implications – for example, the cost of setting up pre-assessment services may be in part offset by fewer cancelled procedures. As yet, key performance indicators have not been formally developed, but as this area of study develops specific KPIs may be created to allow evaluation of unit performance with regards to patient experience. It will be imperative that measures of patient experience are developed robustly and are validated for use.

Patient views on experience are clearly fundamental for a statement such as this. This statement was produced by a group with wide interest in the area of patient experience with many members of the group having studied this field. Although only two patients were part of the formal group, they have extensive experience of endoscopy and represented patient views much more widely.

It is also noted that whilst this statement discusses how patient experience should be assessed, it does not detail when this should be assessed. Real-time feedback during the procedure is clearly important in order to maintain a positive patient experience, and patients should also have the opportunity to feedback about their experience at a later date – indeed, this is recommended in the recent ESGE guidance.[104] At present, there are no patient-derived validated tools to assess patient experience, although large scale studies are underway to develop such tools. Once they are available, discussions in future iterations of this statement should address the timing of collecting patient feedback, along with discussion about methods to obtain this feedback (such as postal surveys, telephone surveys, or online methods). Consideration should also be given to how results from such tools are disseminated, both within the clinical community, but also out to the patient population. It may have bearing on patient uptake of tests, with potential improvement in uptake if positive patient experience can be demonstrated.

Conclusion

This statement provides endoscopy units with a framework to start addressing patient experience of GI endoscopy. This statement is not exhaustive and is likely to evolve over the coming years as the subject area of patient experience expands. It is also currently to be used as a guide for making changes to practice, but in the future, these recommendations may become part of unit certification. As validated, patient-derived methods for assessing patient experience come into use, this statement will need review once their role is clearer.

Box 1. Executive summary
Box 2. Key domains
Figure 1. Diagram of statements included/merged/discarded at each round

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