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A Core Information Set for Surgery for Oesophageal Cancer

On behalf of the Core Outcomes and iNformation SEts iN SUrgical Studies – Oesophageal Cancer Writing*, Research ** and Consensus Groups***

*Members of the writing group: JM Blazeby[#], R Macefield, NS Blencowe, M Jacobs, AGK McNair, M Sprangers, ST Brookes.

**Members of the research group: KNL Avery, JM Blazeby[#], NS Blencowe, ST Brookes, J Elliot, M Jacobs, I Korfage, R Macefield, F Mackichan, J Nicklin, EMA Smets, MAG Sprangers, S Strong , DR Titcomb, MI van Berge Henegouwen, R Whistance, J Witherstone,.

*** Members of the consensus group: R Berrisford, JM Blazeby[#], J Byrne, S Dwerryhouse, S Galloway, SM Griffin, A Hassn, D Hewin, S Higgs, P Lamb, J Manson, R Moxon, S Osbourn, K Pursnani, M Shackcloth, T Underwood, J Whiting.

[#]Corresponding author Professor Jane M Blazeby, email j.m.blazeby@bris.ac.uk

Abstract

Surgeons provide patients with information before surgery although standards of information provision are lacking and practice varies. The development and use of a 'core information set' may improve understanding and decision-making. A core set is a minimum set of information to use in all consultations as a baseline before surgery. This study developed a core information set to use during information provision prior to surgery for oesophageal cancer.

All potential information was identified from the literature, observations of clinical consultations and interviews with patients. The information was synthesised and used to create a questionnaire survey. Stakeholders' (patients and professionals) were surveyed twice to assess views of information importance from "not essential" to "absolutely essential" using Delphi methods. Items not meeting pre-defined criteria were discarded after each survey round. Items retained after the second round were voted on in stakeholders meetings to agree the final core set.

Initially 67 information items were identified from the multiple sources. Survey response rates were good, 76.5% (185/242) and 54.8% (126/230) for patients and professionals respectively (first round) and > 83% in the both groups thereafter. Health professionals rated short term clinical outcomes most highly whereas patients rated longer endpoints as important. In the consensus meetings nine items were identified in the core set to encompass issues of importance to both stakeholder groups.

This study has established a core information set to use for surgery for oesophageal cancer. Further work will evaluate its use in practice.

Introduction

The main stay of curative treatment for oesophageal cancer is surgery which may be combined with neoadjuvant chemotherapy or chemoradiotherapy. Although many advances in surgery for oesophageal cancer have occurred over the past decade, the long term outcomes are generally poor and peri-operative risks remain high[1]. The risk of in-hospital death after oesophagectomy is between 2 and 4%, serious complications occur in about 20% of patients. Surgery also has an immediate major detrimental impact on health-related quality of life (HRQL). Survival after surgery is in the region of 30 to 50% at five years and HRQL deficits persist in long term survivors[2-4]. The decision to undergo this surgery, therefore, is difficult. It is informed by discussion between surgeons and patients about the short term risks and long term outcomes and it includes consideration of tumour stage, patient co-morbidities, and, surgeon and patient preferences. Current United Kingdom and international policy supports the use of shared decision-making between surgeons and patients with exchange of information[5-6]. Whilst there is an emphasis for surgeons to provide high quality information to inform the decisions, the actual information provided in consultations is largely unknown and standards for information provision and methos for informed consent for surgery are limited[7]. Indeed, the driver behind many consultations focuses on the medico-legal requirements for surgeons to discuss inherent risks of surgery rather than focus upon patient information needs[8-10].

Recent surveys in oesophago-gastric cancer and other cancer sites have examined patients' preferences for information[8,10]. Generally patients prefer more rather than less information and studies show that patients want surgeons to raise sensitive issues (such as prognosis) in clinic appointments rather than having to request this information themselves[8-11]. There is therefore recognition that information provision is important, however, the amount of information that could be communicated before surgery is large and it is unclear what information is critical to inform understanding. It is also important to avoid overwhelming patients with data which may reduce understanding[12]. One method for focussed provision of information before surgery is to identify a

'core information (disclosure) set' for specific procedures[13]. Core information represents the minimum information to be disclosed by a clinician in all consultations for a particular operation. The idea of the "core information set" was described in the bioethical literature over 30 years ago where 'core disclosure' was recommended. It was suggested that a 'core disclosure set' would include information of importance to key stakeholders (i.e. patients and surgeons) and be feasible to communicate in a regular clinical consultation. Although a seminal idea, this has hitherto not been further explored[14]. This study presents the development of a core information (disclosure) set for surgeons to use in consultations with patients before surgery for oesophageal cancer and considers how this can be used in future practice to improve shared decision-making and informed consent.

Methods

Development of the core set involved three phases. Phase 1 generated an exhaustive list of all the information that could be communicated before surgery for oesophageal cancer. This long list was reduced by grouping similar pieces of information together and these were used to create questionnaire items. In phase 2 the questionnaire was used to survey stakeholders' views of the importance of each item using Delphi methods. Phase 3 finalised the core information set to be feasible to use in practice through separate consensus meetings with surgeons and patients (Table 1).

Phase 1 – generation of a questionnaire

Several sources were used to identify all possible pieces of information; i) systematic searches of the international clinical and patient reported outcome literature, ii) analyses of written patient information leaflets used for oesophageal cancer surgery in UK hospitals, iii) analyses of audio-recorded consultations between patients and surgeons in which consent for surgery was discussed, and, iv) analyses of interviews with patients prior to surgery[15-19]. Duplicates were removed and a long list of information was created. The clinical items were categorised independently by two

members of the study team into domains (e.g. 30-day and 90-day mortality were within the 'mortality' domain). Patient reported outcomes were grouped into domains (e.g. ability to walk and activity levels were within the physical function domain) and verified by two researchers and a patient representative[15]. Items from patient information leaflets were independently categorised by a surgical registrar and a cancer nurse specialist. Discrepancies were resolved by discussion with the study lead. Overlapping domains between data sources were condensed producing a final list of domains.

The final domains were operationalised into questionnaire items using lay language with the medical terminology included in parentheses. The purpose of the questionnaire was to allow stakeholder groups to rate items from 1 to 9, where 1 was 'not essential' and 9, 'absolutely essential' information. The questionnaire was piloted by four members of a patient support group for face validity, understanding and acceptability. Following this modifications were made. The questionnaire was translated into Dutch by a professional translator and checked by members of the study team.

Phase 2 - Delphi consensus methods

Delphi consensus methods were used to inform consensus on the core information set[20]. The questionnaire developed in Phase 1 was sent to key stakeholders including oesophageal cancer surgeons, clinical nurse specialists and patients who were awaiting or who had undergone surgery for oesophageal cancer (Round 1). Surgeons and nurses were identified via an oesophageal cancer meeting, the UK Association of Upper Gastro-Intestinal Surgeons and by personal knowledge of surgeons in oesophageal cancer surgery centres. Patients were recruited from Bristol and Birmingham in the UK, and from the Academic Medical Centre in The Netherlands. In the UK, participants were approached by post and responders consenting to participate were sent the questionnaire with a stamp addressed envelope. One reminder was posted to patients if necessary.

Health professionals were approached in a similar way with an email reminder if required. In The Netherlands, participants were contacted by telephone and those agreeing to participate received postal questionnaires. Health professionals were contacted by email and then posted questionnaires. First round questionnaires were analysed and participants sent a second questionnaire (Round 2) which contained a reduced number of items. In Round 2, participants were asked to re-prioritise each item. Round 2 questionnaires also contained feedback from Round 1. All questionnaires contained the individual's score 1 and group feedback (summarized as a mean score in order to be readily understood by participants). Some participants had feedback for both stakeholder groups and others had feedback for their own stakeholder group (details of this exploratory substudy will be described separately). Participants were asked to rescore each item between 1 and 9; questionnaires were then analysed to determine which items should be retained and presented in the consensus meetings. The Round 2 survey was carried out using retained items.

Phase 3 – Face to face consensus meetings

Two consensus meetings were held in Bristol; the first with health professionals and the second with patients and carers. Because oesophagectomy represents major surgery and post-operative recovery is often lengthy, carers were also invited to participate in the patients' meeting in recognition of their crucial role in decision making. The meetings were held in January and March 2013 respectively. Attendees were all from the UK and had completed the questionnaire surveys and responded to an invitation to attend a consensus meeting. The retained items from the second survey were presented in the meetings and participants asked to anonymously rate their importance. Anonymised voting took place to ask participants to select 'In', 'Out' or 'Unsure' for each time. Histograms and descriptive statistics were created for each item during the meeting displayed to the participants. Where there were apparent bimodal distributions (similar number of participants voted 'In' or 'Out') these were explored by discussion to see if there was polarized opinion within the stakeholder groups.

Sample size

There are no agreed methods to set the sample size for Delphi surveys or consensus meetings. Therefore an opportunistic approach was used with the aim of obtaining at least 100 respondents for each group for the survey and a group in which discussion could take place (<30) for the consensus meetings.

Data analysis

In Round 1 of the survey, items were categorized as "essential" and retained for Round 2 if they were rated between 7 and 9 by over 50% of respondents *and* between 1 and 3 by less than 15%. Items not meeting these criteria were discarded. Mean scores were calculated for each retained item. The process of discarding items was performed separately for patient and health professional groups. Round 2 responses were analysed with a stricter cut-off criteria, retaining items rated between 7 and 9 by over 70% of respondents, and between 1 and 3 by less than 15%. There are no agreed methods for selecting cut off criteria within Delphi studies therefore the criteria were selected after discussion within the writing group and collaborators. The items retained after Round 2 were considered in phase 3 consensus meetings. In the meeting each item was discussed and voting took place which asked attendees to vote items as 'in', 'out', or, 'unsure'. Voting was undertaken using electronic keypads to ensure anonymity. The unsure items were re-discussed with further voting and discussion. All items retained from both meetings were included in the final core set.

Results

Phase 1

Review of all data sources describing information relating to oesophageal cancer surgery generated 901 individual pieces of information, which were categorised into 67 items within the Round 1

questionnaire. These covered items about immediate and in-hospital surgical complications, longer term side effects, peri-operative processes and experiences, longer term quality of life and cancer survival and related events (e.g. local and distant recurrence).

Phase 2

In Round 1 of the Delphi survey, response rates were 185/242 (76.5%) for patients and 126/230 (54.8%) for health professionals. The majority of patients and health professionals were male (75.1% and 72.2% respectively) (Table 2). In the health professional group 84 (67.7%) were consultant surgeons, 29(23.0%) nurse specialists and 13 (10.4%) were trainees and most, 98 (77.8%), were from the UK. Similar demographics were observed amongst patients from the UK and The Netherlands.

In Round 1 health professionals rated information about short term clinical risks (anastomotic leakage, in-hospital mortality and inoperability) most highly where as long term outcomes (e.g. information about survival, disease recurrence) were rated highest in the patient group (Table 3). By the time of the Round 2 survey, 11 patients had died and 145 of 174 patient questionnaires were returned (response rate 83.3%). The response rate for health professionals in Round 2 was 84.9% (107/126). Demographics of patient and professional participants were similar in Rounds 1 and 2. Provision of group feedback and application of the more stringent cut-off criteria in Round 2 resulted in 20 items being retained for the patient group and 22 items for the professional group. There were 15 overlapping items between groups.

Phase 3 consensus meetings

The two consensus meetings were attended by 18 professionals and 16 patients / 7 carers respectively. In the initial anonymised voting at the professionals' meeting five items were voted 'in', eight 'out', and, nine 'unsure'. In the patients' meeting it was, five 'in', three, 'out' and 12 'unsure' (Table 4). Extensive discussion ensued in both meetings and it was recognised that items sometimes overlapped in content and meaning. Where appropriate, therefore, items were merged to form a single item. For example, it was agreed that items about 'cancer recurrence' and 'survival' should be

combined as a single item ‘overall survival’. Similarly, items about morbidity (re-operation, anastomotic leak and respiratory morbidity) were combined as, ‘in-hospital complications’. In both meetings where items were initially voted ‘unsure’ further discussion and further voting took place (Table 4). There were two items where the stakeholder groups had opposing views; experiences on admission and information about hospital stay. The groups agreed that these were overlapping and they were therefore combined and kept ‘in’ in the final core set. After both stakeholder meetings the two core sets were combined and the final core information set had eight items (Table 5). The logical sequence for discussing items with patients is also shown in Table 5.

Discussion

This study has developed a core information set for surgeons to disclose in consultations with patients undergoing oesophageal cancer surgery. The core set includes items of importance to health professionals and patients. It was developed following detailed scrutiny of the literature and written hospital information leaflets as well as in-depth analysis of current practice and interviews with patients. The final items were selected by an iterative consensus process including views of over 250 health professionals and patients. The core set contains information about processes before surgery and during hospital admission, short term risks and clinical outcomes. It includes items about long term quality of life and survival. It is now recommended that surgeons (and specialist nurses) use the core information set during consultations with patients before surgery. This may catalyse discussion relevant to patients’ information needs and/or the needs of surgeons to expand details related to surgical morbidity. It is recommended that further work to examine how it is optimally communicated in practice is undertaken.

The concept of provision of ‘core information’ for surgery is not new but this is the first attempt that we are aware of to develop a core set and establish methods to do this. Other approaches for uniform information provision and for improving consultations and consent are available. Patient

decision aids are designed to help people make decisions in situations where there are alternative treatments available and there is data from high quality randomised trials describing the different treatments[20]. The purpose and use of decision aids therefore differs to that of a core information set because of the focus of considering treatment alternatives. There are also aids available for communicating information about risks and for supporting patients prior to consultations before surgery[21-23]. These would be useful in the delivery of a core information set, but the development of a core set of information to be used as baseline information provision for a specified operation is unique. Whilst core information sets are recommended to use as minimum information provision it is important to note that the core information can be supplemented with additional information of importance to patients or surgeons.

Although this work is novel and has been carefully conducted with participation from national and international key stakeholder groups there are some methodological limitations. Consensus was obtained by surveys and meetings which may not have appealed to a full range of stakeholders and it is possible that non-participants may value information differently to participants (the response rates for health professionals in the first survey round was 54%), additionally there was a limited number of international health professionals surveyed which may influence generalisability. There is also a concern that this work focussed on pre-operative information provision although patients surveyed had often undergone surgery. The views of patients after surgery may differ from the pre-operative setting. This issue has partly been addressed by work undertaken collaboratively with the Amsterdam group[24]. In this survey patients and health professionals were specifically asked to prioritise information to be received after surgery. This studied showed that patients wanted information about whether the cancer had been removed (and cured), data about eating and drinking and subsequent recovery and possible complications. Both the current work and this work from the Netherlands, therefore highlight the importance of provision of information about long

term survival and quality of life – things of key importance to patients that can be difficult to discuss in consultations because of the sometimes poor long term outcome of surgery.

This work represents the first step in the area of work and now it is necessary to develop methods to best communicate the information in practice. Surgeons are familiar with communicating technical data about surgery and short term risks, they are also trained to talk about a diagnosis of cancer. Imparting sensitive information about prognosis, however, is more difficult and doing this well require training and may be supported by using adjuncts to information provision including graphical presentation of survival data, or information about quality of life outcomes[21, 22, 25, 26]. It is also possible that the core information set could be communicated by different personnel (surgeons and nurses), this could be agreed by local teams and that hospital written information leaflets be designed to contain the core information set. This will ensure uniform information provision from all sources to help patients' gain sufficient understanding to undergo surgery for oesophageal cancer.

Contributions

Writing group: JMB gained funding for the project, led the work, wrote the first draft of the paper and is the guarantor of the work. STB was a co-PI on the grant contributing to the study design, data analyses and staff supervision. MS contributed to the study design and staff supervision and she categorised the PRO health domains. RM, NB and AM contributed to the study design and were involved in all aspects of the project. MJ was involved in the literature reviews, the questionnaire design and data collection and co-ordination in The Netherlands. KA, JN, IK, SS, RW, FM, JE, ES, MvDB, all were involved in the literature work and IK, DT, JE also categorised the health domains. Members of the professional consensus group participated in the Delphi Surveys and attending the consensus meeting in Bristol (RB, JB,SD, SG, SMG, DH, AH, SH, PL, JM, RM, SO, KP, MS, TU, J W). All authors read and commented on the final manuscript.

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Table 1. Summary of methods to develop a core disclosure set

Phase 1	Identification of all information relevant to the decision to undergo surgery – Literature searches to identify clinical outcomes and patient reported outcomes – Observations of clinic consultations and interviews with patients and surgeons to identify information used in practice and considered important – Review of UK written hospital information leaflets for the type of surgery ***This produces a list of all potential information*** – The list is grouped into information domains* – The domains inform questionnaire items to use in phase 2
Phase 2	**Prioritisation of information by key stakeholders** – Stakeholders are surveyed and asked to prioritise each piece of information – Results of the survey are fed back to stakeholders in a second survey (Delphi methods) and they are asked to re-prioritise each piece of information – Data are analysed by the research group using pre-defined criteria to reduce the list of information ***Two information lists, (from patients and health professionals) are ready for phase 3***
Phase 3	Stakeholder consensus meetings – The items are presented to each group and anonymised voting rated items as, 'in', 'out' or 'unsure' – Items rated as 'unsure' are discussed and more voting is undertaken ***The process produces two sets (one selected by patients, one by professionals). These are compared and condensed into one core information set)***

*A domain can be defined as a broad category of information. For example, haemorrhage, the need for blood transfusion and intra-operative blood loss were all categorised into a single domain termed 'blood loss'.

Table 2. Clinical and socio-demographic details of patient participant in the Delphi survey

	Round 1 n=185	**Round 2 n=145**
Mean age in years (range)	66.5 (38.3 to 82.7)	66.6 (38.3 to 80.3)
Gender (% men)	139 (75.1)	109 (75.2)
Institution (%)		
Bristol, UK	89 (48.1)	69 (47.6)
AMC, The Netherlands	96 (51.9)	76 (52.4)
Length of in-patient stay (%)		
< 14 days	110 (59.5)	87 (60.0)
2-4 weeks	53 (28.7)	44 (30.4)
>4 weeks	12 (6.5)	8 (5.5)
Unknown	10 (5.4)	6 (4.1)
Experienced complications requiring a re-operation (%)	29 (15.7)	24 (16.6)
Pre-operative treatment (%)		
Chemotherapy	141 (76.2)	110 (75.9)
Radiotherapy	84 (45.4)	68 (46.9)
Highest level of education (%)		
School GCSE/A level	65 (35.1)	50 (34.5)
Vocational qualification	50 (27.0)	41 (28.3)
University or higher degree	34 (18.8)	29 (20.0)
Other	25 (13.5)	17 (11.7)
Unknown	11 (6.0)	8 (5.5)
Marital status (%)		
Single	9 (4.9)	8 (5.5)
Divorce/separated	14 (7.5)	10 (7.5)
Married/co-habiting	147 (79.5)	115 (79.3)
Widowed	13 (7.0)	11 (7.6)
Unknown	2 (1.1)	1 (0.7)

UK – United Kingdom, AMC – Amsterdam Medical Centre (note no differences were seen between UK and Dutch patients' views in round 1 or round 2)

Table 3. Round 1 mean scores for top 10 items, ranked by stakeholder group

Information Item	Professionals' mean rating (SD), n=126	Information Item	Patients' mean rating (SD), n=185
Anastomotic leak	8.65 (0.93)	Cancer recurrence	7.88 (1.64)
In-hospital death	8.37 (1.39)	Survival	7.80 (1.88)
Type of surgery	8.17 (1.18)	Inoperability	7.74 (1.81)
Long term general health	8.06 (1.47)	Information about risks related to co-morbidity	7.66 (1.67)
Inoperability	8.03 (1.81)	Long term quality of life	7.68 (1.40)
Information about hospital experience	7.98 (1.49)	Recovery milestones after discharge	7.51 (1.74)
Respiratory complications	7.88 (1.52)	Long term general health	7.47 (1.43)
Re-operation	7.86 (1.38)	Anastomotic stricture	7.47 (1.84)
In-hospital recovery	7.83 (1.58)	In-hospital recovery	7.46 (1.59)
Long term quality of life	7.80 (1.63)	Information about hospital experience	7.44 (1.80)

SD = standard deviation

Table 4 Decisions made at the two consensus meetings (Phase 3)

	Item 'In'		Uncertain		Item 'Out'		Initial views		Final decision
	Pt	HCP	Pt	HCP	Pt	HCP	Pt	HCP	
Survival	16	15	3	0	0	3	In	In	Retain 'Overall survival '*
Inoperability	13	14	1	2	5	2	Unsure	In	Retain item
Cancer recurrence	15	12	1	3	3	3	Unsure	In	Retain 'Overall survival '*
Anastomotic leak	12	11	2	2	5	5	Unsure	Unsure	Retain 'in-hospital complications'**
Long term quality of life	16	11	1	0	2	7	In	Unsure	Retain item
In-hospital recovery	16	10	0	2	3	6	In	Unsure	Retain 'recovery milestones'**
Recovery after discharge	11	10	0	0	8	8	Unsure	Unsure	Retain 'recovery after discharge' *
Preparation for surgery	18	9	0	2	1	7	Unsure	Unsure	Retain 'recovery milestones'**
Experience on admission	17	6	0	1	2	11	In	Out	Retain 'recovery milestones'**
Hospital stay & experience	16	7	0	0	3	11	In	Out	Retain 'recovery milestones'**
Type of surgery	11	7	2	2	6	9	Unsure	Unsure	Retain item
In-hospital pain control	12	7	0	1	7	10	Unsure	Unsure	Retain 'recovery milestones'**
Physical function	11	6	2	2	6	10	Unsure	Out	Voted out
Reflux symptoms	13	6	0	2	6	10	Unsure	Out	Voted out
Long term general health	9	4	1	3	9	11	Out	Out	Voted out
Respiratory complications	n/a	10	n/a	5	n/a	3	n/a	Unsure	Retain 'in-hospital complications'**
Re-operation	n/a	10	n/a	0	n/a	8	n/a	Unsure	Retain 'in-hospital complications'**
In-hospital death	n/a	18	n/a	0	n/a	0	n/a	In	Retain item
Role function	n/a	5	n/a	4	n/a	9	n/a	Out	Voted out
Pain/discomfort	n/a	3	n/a	3	n/a	12	n/a	Out	Voted out
Body image/weight loss	n/a	3	n/a	1	n/a	14	n/a	Out	Voted out
Eating and drinking	n/a	15	n/a	0	n/a	3	n/a	In	Retain 'eating & drinking'*
Dumping symptoms	12	n/a	0	n/a	7	n/a	Unsure	n/a	Voted out
Fatigue	10	n/a	0	n/a	9	n/a	Out	n/a	Voted out
Dysphagia	12	n/a	1	n/a	6	n/a	Unsure	n/a	Retain 'eating & drinking'*
Sleeping problems	8	n/a	0	n/a	10	n/a	Out	n/a	Voted out
Follow up arrangements	11	n/a	0	n/a	8	n/a	Unsure	n/a	Retain 'recovery after discharge' *

n/a=not applicable since not retained following the Delphi survey, * item retained & merged with another item, ** item retained & merged with two items

Table 5 The eight items in the final core information set

Experience on admission & in-hospital
☐ Expected in-hospital experiences and milestones to recovery (incl. length of stay & pain control)
☐ Chances of inoperability
☐ Information about major complications (re-operation, leak, respiratory problems)
☐ In-hospital mortality
Experience after discharge (incl. length of stay & pain control)
☐ Expected recovery milestones after discharge & follow up
☐ Impact on eating & drinking in the longer term
☐ Long term overall quality of life data
☐ Long term survival

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