

A nationwide study of the quality of surgical guidelines and written patient information

Lotte Linnemann Rønfeldt¹, Dorthe Hjort Jakobsen², Henrik Kehlet², Henriette Lipczak³ & Kasper Wennervaldt¹

ABSTRACT

INTRODUCTION: Clinical practice guidelines (CPGs) support enhanced post-operative recovery and decrease morbidity. In addition, patient information leaflets (PILs) are associated with enhanced overall outcomes and improved patient satisfaction. The aim of this study was to provide an overview of the quality of CPGs and PILs in cancer surgery departments undertaking pulmonary lobectomy, nephrectomy, cystectomy, whipples, colorectal and ovarian surgery.

METHODS: We conducted a cross-sectional descriptive study within 44 surgical departments in six cancer subspecialties: lung (n = 4), kidney (n = 9), bladder (n = 5), pancreas (n = 4), colorectal (n = 18) and ovarian (n = 4). Local CPGs were assessed according to nine key elements, i.e. discharge criteria and plans for mobilisation, pain management, nutrition, fluid, nausea and vomiting, antibiotics, bowel movements and urinary drainage. The PILs were evaluated using the DISCERN tool.

RESULTS: All departments had CPGs and PILs. Overall, 43% of the departments incorporated all nine key elements in the CPGs. Yet, a third of the CPGs lacked well-defined discharge criteria, and half of the PILs were of poor/very poor quality (48%); the remainder were fair (43%) or good (10%).

CONCLUSIONS: CPGs and PILs are highly available in Danish departments that perform cancer surgery. However, this study revealed that local CPGs lacked discharge criteria, and the majority of the PILs were considered of poor quality, suggesting that post-operative management after cancer surgery is of varying quality.

FUNDING: not relevant.

TRIAL REGISTRATION: not relevant.

The incidence of cancer in Denmark is approximately 35,000 cases per year, and surgery remains an essential part of the treatment with curative intent for most types of cancer [1]. However, surgery carries a risk of post-operative complications. Considerable variation in surgical procedures, length of hospital stay and recovery has been documented within specific cancer specialties in Denmark [2-5].

Evidence-based clinical practice guidelines (CPGs) have become an integrated part of contemporary patient care as a tool to translate evidence into practice, ensuring a high quality of treatment and reducing undesirable variation [6]. Today, guidelines for the perioperative pathway of cancer surgery support the concept in

fast-track surgery: Enhanced Recovery After Surgery [7], to achieve early recovery by focusing on pain management, reduction of surgical stress, early mobilisation, adequate nutrition and fluids, well-described discharge criteria and optimised patient information [8]. Fast-track surgery in cancer care has resulted in shorter length of hospital stay and reductions in the complication rates with no increase in the number of readmissions [7-9]. In 2006, a Danish study revealed that only 59-88% of the surgical departments performing nephrectomy, pulmonary lobectomy, oophorectomy and colectomy had CPGs. Furthermore, the CPGs often lacked key elements, such as objective pain assessment and clear discharge criteria [5]. To standardise surgical cancer care and reduce variability, national CPGs became available in 2009-2011 [10, 11].

High-quality patient information supports patients in taking a more active role in their care and is pivotal for realistic outcome expectations, enhanced compliance and an overall greater satisfaction [12, 13]. Danish legislation supports patient involvement in decisions about their own treatment. Thus, today patients are encouraged to take active part in their treatment. Surgeons typically provide oral information on prognosis, risks and benefits, and discuss the surgical procedure. Written patient information leaflets (PILs) are designed to supplement the oral information by describing the post-operative period, any known complications, and expectations of recovery and sequelae [12]. Yet, providing reliable information adequately – whether orally or in writing – remains a challenge, and the quality of the PILs used in cancer surgery in Denmark is unknown.

The objectives of this study were to assess the contents of existing CPGs in perioperative care and to evaluate the quality of PILs within six cancer subspecialties in Denmark.

METHODS

All hospital departments that are certified to perform cancer surgery within thoracic surgery, urology, gynaecology and gastroenterology were identified and invited to participate.

The departments participated by submitting their local CPGs and PILs, either as electronic documents or as

ORIGINAL ARTICLE

- 1) Department for Documentation & Quality, The Danish Cancer Society
- 2) Section of Surgical Pathophysiology, Rigshospitalet
- 3) The Danish Clinical Registries (RKKP), Denmark

Dan Med J
2018;65(6):A5491

FIGURE 1

Presence of nine key elements in clinical practice guidelines provided by Danish departments performing surgery within six cancer subspecialties (N = 40).

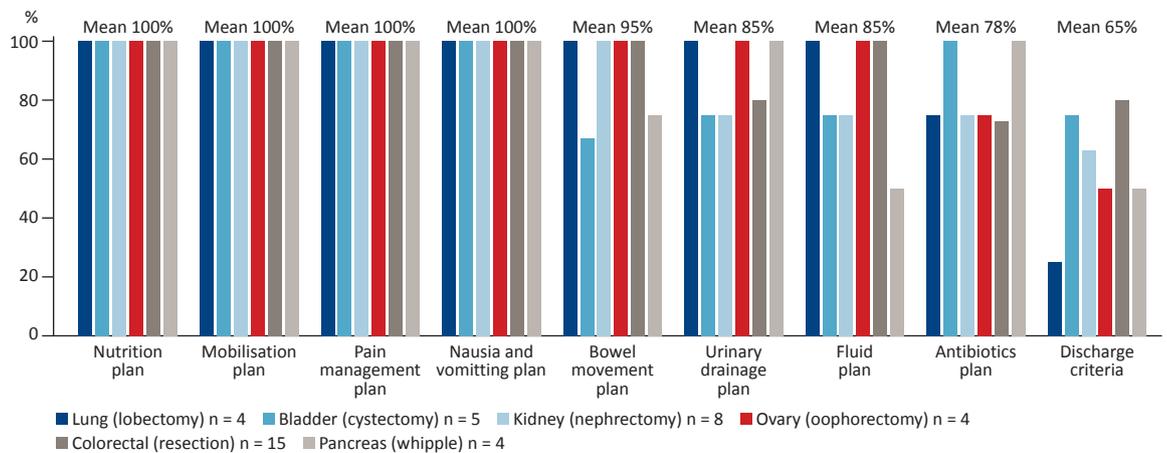
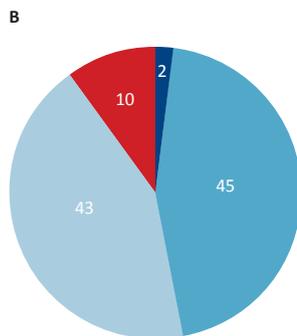
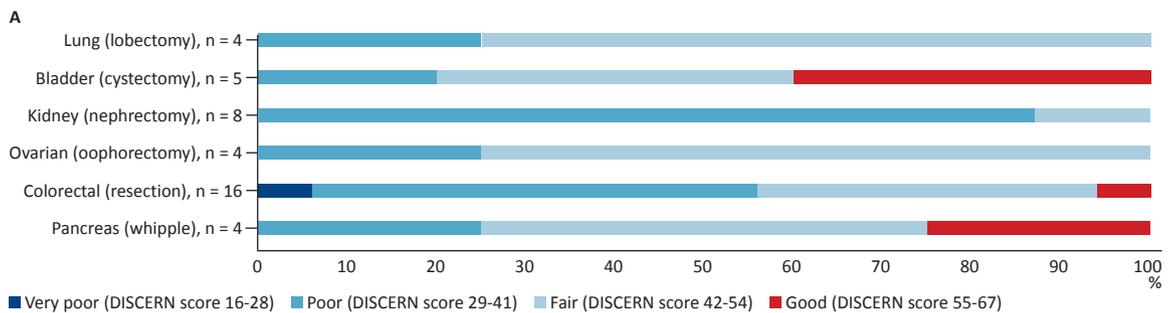


FIGURE 2

The quality (DISCERN) score in patient information leaflets provided by Danish departments performing surgery within six cancer subspecialties (A) and in total (B) (N = 42).



printed paper copies. Each included CPG and PIL was assigned a unique identifier to anonymise the information. Some departments had separate PILs for the same procedure. In such cases, each was reviewed and subsequently scored as one. In case of inconsistency within a pair, the scores from the better performing PIL were chosen.

We assessed the local CPGs focussing on key elements for enhanced recovery after surgery, represented in the national procedure-specific CPGs, i.e. plans for

1) mobilisation, 2) nutrition, 3) fluids, 4) pain management, 5) post-operative nausea and vomiting, 6) antibiotics, 7) bowel movement, 8) urinary drainage and 9) discharge criteria [10, 11]. The quality of PILs was reviewed and scored using a validated DISCERN instrument. The DISCERN instrument evaluates the reliability and quality of the written information concerning diseases and treatments by requiring a response to 16 questions, producing a total score ranging from 16 to 80 [14]. Raters assigned each question a score on a five-



TABLE 1

Patient information leaflets (PILs) performance by question: DISCERN score, mean (range). The quality of PILs by each cancer subspecialty (N = 42).

Criterion	Cancer subspecialty						All
	lung (n = 4)	bladder (n = 5)	kidney (n = 9)	ovarian (n = 4)	colorectal (n = 16)	pancreas (n = 4)	
1: aims clearly described	4.8 (4-5)	4.4 (2-5)	2.6 (1-5)	4.0 (1-5)	3.5 (1-5)	5.0 (5-5)	3.6 (1-5)
2: aims achieved	3.8 (3-4)	4.4 (3-5)	3.1 (2-4)	3.8 (3-4)	3.7 (2-5)	4.0 (4-4)	3.6 (2-5)
3: relevance	4.0 (4-4)	3.8 (3-4)	3.4 (3-4)	4.0 (4-4)	3.6 (2-5)	4.0 (4-4)	3.6 (2-5)
4: sources of information	1.0 (1-1)	1.0 (1-1)	1.0 (1-1)	1.0 (1-1)	1.1 (1-1)	1.0 (1-1)	1.0 (1-1)
5: date of publication	4.0 (1-5)	3.4 (1-5)	4.6 (4-5)	5.0 (5-5)	5.0 (1-5)	5.0 (5-5)	4.5 (1-5)
6: balanced/unbiased	3.8 (3-4)	3.8 (3-4)	3.8 (3-4)	3.8 (3-4)	3.4 (2-4)	4.0 (4-4)	3.6 (2-4)
7: support/other sources	1.0 (1-1)	1.4 (3-3)	1.0 (1-1)	1.5 (1-3)	1.3 (1-3)	1.5 (1-3)	1.2 (1-3)
8: grey areas of treatment	1.0 (1-1)	2.2 (1-4)	1.0 (1-1)	1.0 (1-1)	1.4 (1-4)	1.5 (1-3)	1.3 (1-4)
9: description of treatment	3.3 (2-4)	3.8 (2-5)	2.3 (1-4)	3.3 (2-4)	3.0 (1-4)	3.8 (2-5)	3.0 (2-5)
10: benefits of treatment	1.5 (1-3)	3.4 (1-5)	2.7 (2-4)	2.3 (1-4)	2.8 (1-5)	2.5 (1-5)	2.6 (1-5)
11: risks of treatment	2.8 (1-4)	4.0 (3-5)	3.1 (1-4)	3.8 (3-4)	3.7 (1-3)	3.0 (2-4)	3.4 (1-5)
12: results of no treatment	1.0 (1-1)	2.6 (1-5)	1.0 (1-1)	1.0 (1-1)	1.2 (1-3)	2.0 (1-5)	1.3 (1-3)
13: quality of life	3.3 (3-4)	3.6 (3-4)	2.6 (2-4)	2.5 (2-3)	2.3 (1-3)	3.3 (3-4)	2.6 (1-4)
14: alternatives described	1.0 (1-1)	3.2 (1-5)	1.0 (1-1)	1.3 (1-2)	1.9 (1-5)	2.0 (1-5)	1.7 (1-5)
15: support shared decision	3.0 (3-3)	3.8 (3-5)	2.3 (2-3)	3.0 (3-3)	3.1 (1-4)	3.3 (3-4)	3.0 (1-5)
16: overall score	2.8 (2-3)	3.8 (2-5)	2.3 (2-3)	2.8 (2-3)	2.7 (2-4)	3.3 (3-4)	2.7 (2-5)
Total DISCERN score ^a	41.8 (36-46)	52.6 (31-67)	37.8 (32-42)	43.8 (37-48)	43.7 (26-63)	49.0 (41-62)	42.8 (26-67)
Score per question ^b	2.6 (2.3-2.9)	3.3 (1.9-4.2)	2.4 (2.0-2.6)	2.7 (2.3-3.0)	2.7 (1.6-3.9)	3.1 (2.6-3.9)	2.7 (1.6-4.2)

a) Min. = 16; max. = 80.

b) Min. = 1; max. = 5.

point Likert scale (one for a low quality with extensive shortcomings, five for a high quality with minimal shortcomings). The 16 questions were divided into sections; i) reliability (question Q1-Q8), ii) treatment options (question Q9-Q15) and iii) overall quality (question Q16). Summarised DISCERN scores were categorised as *very poor* (score: 16-28), *poor* (score: 29-41), *fair* (score: 42-54) *good* (score: 55-67) or *excellent* (score: 68-80) [14].

The local CPGs and the PILs were assessed individually by two researchers with a medical background. Inter-rater reliability was not evaluated as previous studies have found a strong index of agreement between coders when using the DISCERN instrument [15]. In the present study, only a few minor disagreements occurred, which were resolved by discussion.

Trial registration: not relevant.

RESULTS

Of 44 departments performing surgery for lung, bladder, kidney, ovary, colorectal and pancreatic cancer, 40 departments provided CPGs (response rate = 91%) and 42 provided PILs (response rate = 95%).

All departments (n = 40) had local CPGs for perioperative care. Divided by subspecialty, 60% (n = 9) CPGs in colorectal surgery included all the nine key elements for enhanced recovery, 50% (n = 2) in oophorectomy, 50% (n = 2) in Whipple's resection, 25% (n = 2) in nephrecto-

my, 25% (n = 1) in pulmonary lobectomy and 20% (n = 1) in cystectomy. Overall, 17 (42.5%) of the CPGs incorporated all nine elements, 11 incorporated eight (27.5%) or seven (27.5%), while one (2%) incorporated six key elements. No CPGs had less than six elements.

Figure 1 shows the presence of the key elements in the local CPGs. All CPGs contained plans for nutrition, mobilisation, pain management and post-operative nausea and vomiting, while most had plans for bowel movement, fluid, urinary drainage and antibiotics. Only 65% of the CPGs (n = 26) had well-defined discharge criteria; this percentage was highest in departments performing colorectal surgery (80%) and lowest in departments performing pulmonary lobectomy (25%).

Figure 2 summarises the assessment of information quality in the 42 PILs. One PIL was very poor (2.3%), 19 were poor (45.2%), 18 were fair (42.9%), four were good (9.6%), and none were excellent. The total mean score was 42.8 (26-67) corresponding to fair (see **Table 1**). The PILs for cystectomy had the highest total score at 52.6 (31-67), i.e. good, while nephrectomy had the lowest score at 37.8 (32-42), i.e. poor. PILs for lobectomy, oophorectomy, Whipple and colorectal surgery were considered fair with mean scores of 41.8 (36-46), 43.8 (26-63), 43.8 (37-48) and 49.0 (41-62), respectively.

Table 1 shows how the PILs performed for each question on the five-point scale. The average mean score was 2.7. Two PILs in cystectomy (5%) achieved a

 TABLE 2

The quality of patient information leaflets provided to patients in Danish cancer surgery using DISCERN tool (N = 42). The values are n (%).

Section	Very poor: score 16-26	Poor: score 27-38	Fair: score 39-50	Good: score 51-62	Excellent: score 63-80
i: reliability ^a	1 (2)	7 (17)	29 (69)	5 (12)	-
ii: treatment options ^b	2 (5)	23 (55)	12 (29)	2 (5)	3 (7)
iii: overall quality ^c	1 (2)	16 (38)	20 (48)	3 (7)	2 (12)

a) Q1-Q8 DISCERN score: min. = 8; max. = 40.

b) Q9-Q15 DISCERN score: min. = 7; max. = 35.

c) Q16 DISCERN score: min. = 1; max. = 5.

mean score of 4.0 or higher, indicating that the quality criteria were almost met, whereas four PILs (10%) achieved a mean score of 2.0 or lower (one in cystectomy and nephrectomy, two in colorectal surgery), indicating serious shortcomings. Overall, questions Q4, Q7, Q8, Q12, Q14 had DISCERN scores below 2.0. The lowest scoring question was “sources of information” used to compile the PIL (other than the hospital unit or doctor) (Q4), as none of the PILs reported this. The highest scoring question at 4.5 concerned the topic “visible date of publication” (Q5).

Table 2 shows the quality of the PILs within the three DISCERN sections. The PILs were considered fair regarding reliability (n = 29 ≈ 69%) and overall quality (n = 20 ≈ 48%). However, the majority of PILs had a poor quality of treatment information (n = 23 ≈ 55%).

DISCUSSION

Standardised care needs to be supported by evidence-based CPGs in order to ensure quality and safety, and “close the gap” between what is known and what is done [6]. Although CPGs have the potential to enhance recovery after surgery, decrease morbidity and shorten hospital stay for several major cancer surgical procedures [8], development and implementation of CPGs have been slow in Denmark [10].

This study shows that availability of CPGs and integration of key elements for fast-track surgery have improved considerably since 2006 [5]. However, the content of the CPGs is inconsistent, and details in recommendations and daily goals vary – both across and within the subspecialties. Furthermore, discharge criteria, as an essential objective for the perioperative care in order to ensure a safe discharge, are absent in every third CPG. Thus, discharge criteria still appear as lacking as they did ten years ago [5]. However, the CPGs in colorectal cancer surgery are on forefront regarding discharge criteria, reflecting a dominance in scientific documentation and data from more than 20 years [9].

In 2004, the introduction of fast-track programmes

was prioritised politically in Denmark and the Unit of Perioperative Nursing was established [10]. In the 2004-2012 period, the Unit systematically compiled national procedure-specific CPGs and underpinned implementation, thereby providing easily accessible evidence to clinicians. The Unit enabled reliable monitoring of quality in surgery to provide feedback to clinicians and researchers highlighting inappropriate practice variations and areas where research was needed [10, 16]. Today, ensuring accurate and up-to-date CPGs is a continuous challenge for the surgical departments.

To provide patients and relatives with important and relevant information, written patient information has the potential to engage patients in their own post-operative care and rehabilitation, supplementing the oral information as well as enabling a better patient-clinician dialogue [13]. In this study, half of the PILs provide information of poor quality to cancer patients, whereas most of the remaining PILs are of a fair quality. Furthermore, the majority of PILs do not adequately convey the necessary information about the treatment and none refers to the underlying evidence. An international study of patient information in colorectal cancer showed that > 50% were of poor quality and most of the remainder were of average quality [17]. Our results are consistent with findings for other treatments and medical conditions and with studies concerning information available for patients undergoing cancer surgery, finding that most of the information is of suboptimal quality [18, 19].

The variation in the quality of PILs in the present study reflects a lack of consistency when producing and maintaining PILs, and indicates that health professionals may have trouble translating evidence into written information. As a result, the potential to enhance patient understanding and participation in decision-making and self-care is not exploited. Nevertheless, the results in bladder cancer with 60% of the PILs being of good quality show that some departments do attach importance to the quality of PILs and demonstrate that it is possible to reach higher standards.

This study reveals that currently, a third of PILs were poor and the majority failed to provide basic information such as treatment options or analysed it poorly. Specifically, information on the consequences of non-treatment and information related to alternatives to surgical management of cancer is almost absent (Q12, Q14), as only four PILs (9.5%) mentioned the implications of not undergoing surgical treatment, and 14 PILs discussed alternatives to surgery (33.3%). Given the increased attention towards empowering patients to be active in their own health care, our results highlight the importance of enhancing the quality of PILs.

Limitation

This evaluation of CPGs and PILs in Danish cancer surgery is based on material submitted from the participating departments; this material does not necessarily reflect clinical practice. Furthermore, the quality of the recommendations in the local CPGs was not evaluated in this study, e.g. whether they were comprehensive, adequate or matched evidence. Since the details in the local CPGs seem to vary considerably, analysis with a reliable tool would add further to the assessment of quality.

Although a valid tool for assessing written health information, the DISCERN instrument has a number of limitations. It cannot be used to evaluate the scientific reliability (i.e. concordance with the CPGs), nor does it take into account readability or requirements for health literacy. In addition, classifying the DISCERN scores into categories by chosen quality cut-off values is done arbitrarily.

The assessment of the local CPGs and PILs was performed by two researchers to ensure the reproducibility of the scores. However, it remains unknown if laypersons would assess the written information in the same manner.

CONCLUSIONS

This study examined the contents of local CPGs that were available for perioperative care and the quality of information in PILs provided for major surgery in Denmark, using lung, kidney, bladder, ovarian, colorectal and pancreatic cancer.

Currently, most local CPGs contain key elements for enhanced recovery after surgery. However, delineated discharge criteria were often missing and recommendations in the plans and also daily goals varied. The quality of the CPGs has yet to be evaluated by a valid instrument, and improvement activities should address inconsistencies and imprecision across departments within the same specialty – by motivating a culture striving towards transparency and shared learning between departments and across specialties.

To the best of our knowledge, this is the first study to evaluate the quality of health information in PILs provided to patients facing major cancer surgery. Overall, few PILs provided high-quality information, whereas almost half of the PILs were of fair or poor quality, respectively.

The Danish Health Authority has placed revision of national clinical guidelines for cancer treatment and provision of information to facilitate patient choice of treatment at the centre of its vision for future healthcare management [20]. Hence, an opportunity exists for the medical professions to enhance recovery through a co-

ordinated quality improvement, research and implementation of evidence-based practice. A focus on reviewing current CPGs, supporting implementation and monitoring initiatives, and on creating high quality and comprehensive PILs may serve as a pillar support for both clinicians and patients. Establishing a national unit could facilitate this process.

CORRESPONDENCE: Lotte Linnemann Rønfeldt. E-mail: lotterf@cancer.dk

ACCEPTED: 23 April 2018

CONFLICTS OF INTEREST: none. Disclosure forms provided by the authors are available with the full text of this article at www.danmedj.dk

ACKNOWLEDGEMENTS: A special thanks to members of the group behind The National Initiative for Patient Safety in Cancer Treatment and Care (NIPK) and to all participating cancer surgical departments for providing the study data.

LITERATURE

- Engholm G, Ferlay J, Christensen N et al. NORDCAN: cancer incidence, mortality, prevalence and survival in the Nordic countries, Version 7.3. Copenhagen: Association of the Nordic Cancer Registries. Danish Cancer Society, 2015.
- Kehlet H, Dahl JB. Anaesthesia, surgery, and challenges in postoperative recovery. *Lancet* 2003;362:1921-8.
- Jensen LS, Bendixen A, Kehlet H. Organisation and early outcomes of major upper gastrointestinal cancer surgery in Denmark 1996-2004. *Scand J Surg* 2007;96:41-5.
- Marx C, Bendixen A, Hogdall C et al. Organisation and quality of primary surgical intervention for ovarian cancer in Denmark. *Acta Obstet Gynecol Scand* 2007;86:1496-502.
- Rud K, Jakobsen DH, Egerod I et al. Surgical care guidelines. *Ugeskr Læger* 2008;170:1559-63.
- Grimshaw JM, Russell IT. Effect of clinical guidelines on medical practice: a systematic review of rigorous evaluations. *Lancet* 1993;342:1317-22.
- Kehlet H, Wilmore DW. Evidence-based surgical care and the evolution of fast-track surgery. *Ann Surg* 2008;248:189-98.
- Kehlet H. Fast-track surgery-an update on physiological care principles to enhance recovery. *Langenbecks Arch Surg* 2011;396:585-90.
- Varadhan KK, Neal KR, Dejong CH et al. The enhanced recovery after surgery (ERAS) pathway for patients undergoing major elective open colorectal surgery: a meta-analysis of randomized controlled trials. *Clin Nutr* 2010;29:434-40.
- Jakobsen DH, Rud K, Kehlet H et al. Standardising fast-track surgical nursing care in Denmark. *Br J Nurs* 2014;23:471-6.
- <https://www.rigshospitalet.dk/afdelinger-og-klinikker/julianemarie/enhed-for-perioperativ-sygepleje/accelerede-operationerforloeb/Sider/default.aspx> (7 Jun 2017).
- Grime J, Blenkinsopp A, Raynor DK et al. The role and value of written information for patients about individual medicines: a systematic review. *Health Expect* 2007;10:286-98.
- Epstein RM, Street RL. Patient-centered communication in cancer care: promoting healing and reducing suffering. Bethesda: National Cancer Institute, 2007.
- Charnock D, Shepperd S, Needham G et al. DISCERN: an instrument for judging the quality of written consumer health information on treatment choices. *J Epidemiol Community Health* 1999;53:105-11.
- Rees CE, Ford JE, Sheard CE. Evaluating the reliability of DISCERN: a tool for assessing the quality of written patient information on treatment choices. *Patient Educ Couns* 2002;47:273-5.
- The Danish Clinical Registries. <http://rkkp.dk/om-rkkp/den-danske-kliniskedatabaser/> (7 Jun 2017).
- Wasserman M, Baxter NN, Rosen B et al. Systematic review of internet patient information on colorectal cancer surgery. *Dis Colon Rectum* 2014;57:64-9.
- Blencowe NS, Strong S, McNair AG et al. Assessing the quality of written information provision for surgical procedures: a case study in oesophagectomy. *BMJ Open* 2015;5:e008536.
- Langbecker D, Janda M. Quality and readability of information materials for people with brain tumours and their families. *J Cancer Educ* 2012;27:738-43.
- The patients' cancer plan – Cancer Plan IV. Copenhagen: Danish Ministry of Health, 2016.