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PET/CT in oncology

*Patient experience, image quality and the value of
information*

CAMILLA ANDERSSON



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Abstract

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The overall aim was to investigate patients' experiences with a PET/CT examination, satisfaction with care provided in connection to the examination and whether web-based information can improve satisfaction with care and image quality, compared to standard care. An additional aim was to explore how satisfaction with care and image quality is associated with health-related quality of life (HRQoL) and perceived stress. *Methods:* Study I and IV included patients with known or suspected malignancy scheduled for an ¹⁸F-FDG PET/CT examination. Study II included prostate cancer patients with known or suspected bone metastases scheduled for an ¹⁸F-fluoride PET/CT examination, and study III included head and neck cancer patients scheduled for an ¹⁸F-FDG PET/CT examination in a fixation mask. Study I and II had cross-sectional designs, study III used a phenomenological methodology according to Max van Manen, and study IV was a randomized controlled trial. *Results:* Study I and II found that many patients did not know before what a PET/CT examination was but were satisfied with care provided by the nursing staff. In study II the image quality was high and there was no difference in image quality between those patients that experienced pain or discomfort during the PET/CT and those that did not. Study III showed that the patient's lifeworld was changed during the PET/CT examination and the use of coping strategies helped the patient to endure the examination procedure. In study IV the overall satisfaction, satisfaction single-variables and image quality was high in the intervention group and standard care group. There was no statistically significant difference between patients the intervention group and standard care group. However, there was slightly higher number of detected image quality defects in the standard care group. In study I and IV there were some statistically significant correlations between patient satisfaction and HRQoL ($p < 0.01-0.05$). *Conclusion:* The results of this thesis may be used to improve patient information and care in connection to PET/CT examinations and thereby help optimize PET/CT imaging procedure. However, the results need to be investigated in larger populations.

Keywords: PET/CT, patient experience, image quality.

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List of Papers

This thesis is based on the following papers, which are referred to in the text by their Roman numerals.

- I Andersson, C., Johansson, B., Wassberg, C., Johansson, S., Ahlström, H., Wikehult, B. (2015). Patient experiences of an ^{18}F -FDG-PET/CT examination: Need for improvements in patient care. *Journal of Radiology Nursing*, 34:100-108.
- II Andersson, C., Johansson, B., Wassberg, C., Johansson, S., Sundin, A., Ahlström, H. (2016). Assessment of whether patients' knowledge, satisfaction, and experience regarding their ^{18}F -fluoride PET/CT examination affects image quality. *Journal of Nuclear Medicine Technology*, 44 (1):21-25.
- III Andersson, C., Röing, M., Tiblom Ehrsson, Y., Johansson, B. (2017). It's a question of endurance – Patients with head and neck cancer experiences of ^{18}F -FDG PET/CT in a fixation mask. *European Journal of Oncology Nursing*, 29:85-90.
- IV Andersson, C., Trampal Pulido, C., Ahlström, H., Johansson, B. (2017). Effects of web-based information on patient satisfaction and image quality in patients undergoing an ^{18}F -FDG PET/CT examination – a randomized controlled trial. *Manuscript*.

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Abbreviations

CT	Computed tomography
EORTC-QLQ-C30	European organization of research and treatment of cancer-quality of life questionnaire-core 30
EORTC-QLQ-PR25	European organization of research and treatment of cancer-quality of life questionnaire-prostate cancer module
FDG	¹⁸ F-fluoro-2-deoxyglucose
HRQoL	Health-related quality of life
LMS	Learning management system
MRI	Magnetic resonance imaging
PEQ29	Patient experience questionnaire-29 item
PET	Positron emission tomography
PET/CT	Positron emission tomography/computed tomography
PSS	Perceived stress scale-10 item
QoL	Quality of life
SPECT	Single-photon emission computed tomography

Prologue

I began working as a nurse at the nuclear medicine department at Uppsala University Hospital in 2003. In this department, we conduct many different kinds of nuclear medicine examinations and radionuclide therapies, and as a nurse, you meet many different patients in all age groups, outpatients and inpatients. The majority are cancer patients. This group of patients is vulnerable, and all patients have their own individual thoughts and feelings about the upcoming examination or radionuclide therapy at the nuclear medicine department. Since the examinations require patient cooperation during the procedure, my experience was that as a nurse, you are accountable for making sure the patient perceives the information correctly and through functioning communication and interactions with the patient during the procedure, thus ensuring a satisfactory examination result and high image quality. In 2008, we obtained our PET/CT camera which has primarily been used for ^{18}F -FDG PET/CT examinations in clinical routine. Since this was a new diagnostic examination at our department at that time, I started to think about how patients experienced undergoing the PET/CT examination, which required both pre-examination preparations and patient adherence to instructions during the examination. I also began to wonder about how patients perceived information about the examination and whether and how the communication and interactions between patients and nursing staff affected patients' experience and their motivation and ability to follow the required instructions. I was interested in knowing more about what could be done to improve patient information, satisfaction and comfort during the examination procedure and thereby also contribute, hopefully, to patient satisfaction and high image quality. At that time, there was a lot of research regarding different aspects of PET/CT, but very little about the patient perspective and none at our department. I spoke to a senior researcher about my thoughts and ideas, and thus began the long and winding journey.

Background

Imaging in oncology

In oncology, care and management of patients with known or suspected cancer imaging has an important role. A variety of different imaging techniques are available to use in today's oncological care due to the development in imaging in recent decades such as, computed tomography (CT), magnetic resonance imaging (MRI), bone scintigraphy and positrons emissions tomography (PET) in combination with CT, which yields the hybrid imaging technique (PET/CT).¹ Hybrid imaging such as, PET/CT and single-photon emission computed tomography (SPECT)/CT have proven superior regarding diagnostic accuracy compared to either techniques alone.² There are a number of factors to consider when choosing a specific imaging technique such as, the known or suspected malignancy, the purpose of the examination and the individual patient.¹

PET/CT

PET combined with CT is a non-invasive hybrid imaging technique. PET provides biochemical and functional information about target tissues while CT provides information about morphological and anatomical structures.³ The CT image is created by x-rays and the PET image by radioactively labelled isotopes (tracers) which are injected intravenously into the patient.³ One of the most commonly used tracers in oncology is ¹⁸F-fluoro-2-deoxyglucose (FDG), which is a glucose analogue. Since many cancers have increased consumption of glucose, the ¹⁸F-FDG PET/CT examination has thereby proven to be a valuable tool for diagnosis, staging, evaluating therapy response and radiotherapy planning regarding lung cancer, malignant lymphoma, malignant melanoma, colorectal cancer and head and neck cancer.³⁻⁶ ¹⁸F-fluoride is a bone seeking tracer which may be used to detect skeletal abnormalities such as metastases in patients with prostate cancer.^{7,8} The ¹⁸F-fluoride PET/CT examination has improved diagnostic accuracy of bone metastases compared to bone scintigraphy.^{9,10}

The cancer patient

According to National Board of Health and Welfare, were approximately 61000 people diagnosed with cancer in Sweden in 2015, prostate cancer and breast cancer were the most common diagnosis and lung cancer had the highest mortality rate.¹¹ Cancer-related fatigue is one of the most common side-effects of cancer and cancer treatment and may negatively affect every aspect of quality of life (QoL) of the cancer patient.^{12,13} It is experienced of the patient as a subjective feeling of being very tired and may appear even when the patient is free from the disease.¹² The mechanism behind cancer-related fatigue is somewhat unclear but there are a number of risk factors that have been identified such as; depression, sleep-disturbance and low physical activity.¹³ The cancer patient may also experience other symptoms. Patients with prostate cancer, especially with metastatic disease may experience pain¹⁴ and the patient with head and neck cancer may experience difficulties to i.e. breathe and speak due to the disease and its treatment.^{15,16} Lung cancer patients experience unmet supportive care needs such as fatigue which have an impact on the patient's well-being and satisfaction with care.¹⁷ According to guidelines and local regulations, does the PET/CT examination require the patient to follow instructions and actively participate during procedure i.e. to be positioned supine on the PET/CT scanner bed with the arms elevated over the head and remain in the same position during the PET/CT acquisition.^{18,19} This may potentially be uncomfortable or distressing for some patients who are experiencing fatigue, pain or dyspnea. It also requires nursing staff to ensure that care is adapted to needs of the individual patient and may be of importance for the patient's satisfaction with care.

Quality of care

Quality of care is a term that is often used in healthcare although it is not easy to define clearly.^{20,21} However, it is dependent on the interpersonal interactions between the patient and the health-care professional.²⁰ Interpersonal skills require communication and the ability to build a relationship of trust, understanding and empathy with the patient.²¹ Patient satisfaction may be an indicator of quality of care and satisfaction itself is dependent on many factors such as communication, information and the interpersonal relationship between the patient and nursing staff.²² There are two domains that may define quality of care,²³ access and effectiveness. Access means the patients can get the care they need when they need it; effectiveness means that the healthcare delivers what was intended in such a way that suits the patient's needs.²³ According to Allen-Duck *et al*, healthcare quality is the result of effective and safe care delivered in a culture of excellence and re-

sulting in desired or optimal patient health.²⁴ In the context of PET/CT examinations, quality of care could mean the patient gets the requested time for the examination (access) and care targeted to the patient's individual needs (effectiveness). This in turn may hopefully lead to a satisfied and well-informed patient who is able to contribute to high image quality.

Patient experience and satisfaction with care

In modern healthcare new diagnostic examinations are rapidly developing and many patients are aware of the increasing number of different examination options that are available. This may lead to patients having higher expectations and demands when they are to undergo a diagnostic examination. Patient' satisfaction may be dependent on their experience with health care i.e. if they received enough information, individualized care and good communication.²⁵ There is also a difference if the patient is satisfied or very satisfied. If the patient is very satisfied, it could be, for instance, that the experienced care had something "extra", or that care was experienced as complete or outstanding, which could mean nothing was missing.²⁵ Some studies have investigated patient experiences and satisfaction regarding different types of diagnostic examinations.²⁶⁻²⁹ Patients undergoing a cardiac SPECT/CT examination Nightingale *et al.* and MRI Törnqvist *et al.* were satisfied with care overall, but may experience anxiety in connection to the examination. Information about the procedure before and explanations during the cardiac SPECT/CT and MRI examination procedure may help reduce this anxiety, as well as support and reassurance from the nursing staff.^{28,29} A study by Harding *et al.* investigated patient satisfaction at a nuclear medicine department regardless of which examination the patient was planned to undergo. They found that patients were satisfied overall with the information and care in connection to the examination. The lowest satisfaction scores were regarding environmental factors, which in some cases may be hard to control.²⁶ Similar results were found by De Man *et al.* who investigated patient and staffs perceptions of service quality at a nuclear medicine department. Patients were satisfied with care overall during their appointment at the department. However, to increase patient satisfaction it is suggested to improve the nursing staff professional skills and the department's physical components. It was also revealed that the staff appear to be underrating overall patient satisfaction.²⁷ Recent studies show that patients may experience anxiety before, during and after an ¹⁸F-FDG PET/CT examination.^{30,31} The most common cause of this anxiety was fear of the results of the ¹⁸F-FDG PET/CT examination.³¹ Reduced anxiety associated with the ¹⁸F-FDG PET/CT examination may increase patient satisfaction and the knowledge that patients can be in contact with the nursing staff during the procedure i.e. with the help of a call device may help reduce this anxiety.³² These studies focused on patient anxiety in connection with the ¹⁸F-FDG PET/CT exami-

nation³⁰⁻³² and not on patient experiences and satisfaction with care during the ¹⁸F-FDG PET/CT, and whether this might affect image quality or if patients' experiences and satisfaction with the examination were affected by factors such as; the level of perceived stress and health-related quality of life (HRQoL).

Patient information

Many diagnostic examinations require patients to understand and follow pre-examination information and instructions during the examination procedure to ensure high image quality. Written information before a cardiac SPECT/CT examination and repeated information and explanations during the procedure helped reduce patient anxiety and distress.²⁹ Patients who considered themselves to be well-informed about their CT examination experienced less anxiety than those who stated they were badly informed.³³ Extended written information before an MRI helped patients remain still during the procedure and thus reduced the presence of motion artifacts.^{34,35} Today, people may use the internet as a source of information. Cancer patients are no exception. It has been reported that these patients increasingly use the internet to gather information regarding their diagnosis and treatment options.^{36,37} However, it should be noted that the information that is available on the internet regarding radiological examinations may not always be correct and it is suggested to direct patients to web-sites with reliable information.³⁸ The internet also makes it possible to provide information about different diagnostic examinations to patients who will undergo these examinations. There have been some studies regarding the use of web-based interventions and information before an examination. Ketelaars *et al.* investigated whether online video information before a colposcopy helped to reduce anxiety levels in the women attending the examination. They found that it did not reduce levels of anxiety or pain. However, the video was experienced positively by the patients and is thus recommended for use prior to a colposcopy, especially with more anxious patients.³⁹ A study by Lin *et al.* investigated whether a web-based educational material in addition to standard information had a positive impact on women's intentions and perceptions about undergoing a mammography examination. They found that it had a positive impact on the patients' intentions and perceptions about having a mammography examination.⁴⁰ However, no previous studies on web-based patient information and PET/CT examinations have been found.

Methods for measuring patient experience and satisfaction

A questionnaire may be used to measure the individual patients' perception and knowledge of various topics in large populations.⁴¹ This method has been used in studies regarding patients experience and satisfaction with un-

dergoing examinations at nuclear medicine departments and PET/CT.^{26,27,30-32} However, there are various aspects to consider when constructing a questionnaire to ensure good psychometric properties such as validity and reliability.⁴² It is important to formulate the questions so that they may be understood by the respondent and the order of the questions. The validity of the results is also depended on the response rate.⁴¹ If an already existing questionnaire is chosen to measure patient experience of health-care quality is it important that it fits the purpose of the present study to ensure a good validity and reliability.⁴² Questionnaires may need to be supplemented with other forms of research methods to gain a deeper understanding of patient experience of care in connection with diagnostic imaging.

Phenomenology focuses on the individual's experiences with phenomena and is both a qualitative research method and a philosophy. The philosophy was founded by Edmund Husserl.⁴³ Phenomenology has inspired human science researchers in different disciplines as they study how people experience the world, for example Max van Manen in pedagogy.⁴⁴ Researchers aim to describe the variations in how individuals experience a phenomenon, and capture the essence of the shared experience of the phenomenon that is common to all individuals.⁴⁵ Max van Manen's method is based on the four fundamental existentials: lived space, lived body, lived time and lived relation, which forms our lifeworld.⁴⁶ Lived space is the world or our surroundings and how it makes us feel. Lived body is our physical and bodily preference. Lived time is our subjective orientation in the past, present and future. Lived relation is our subjective relationship to others.⁴⁶ This method has been used in a previous study on the experiences of sickness and treatment among patients with head and neck cancer.⁴⁷ It is thereby emphasized that phenomenology according to Max van Manen, may be used to gain insight into the lifeworld and provide knowledge about the experiences of patients with head and neck cancer upon undergoing an ¹⁸F-FDG PET/CT examination in a fixation mask, through the their descriptions of lived space, lived body, lived time and lived relation during the examination procedure.

Image quality

The ¹⁸F-FDG PET/CT examination requires the patient to follow pre-examination instructions and instruction from nursing staff during the examination procedure. Patient adherence to instructions is required in order to optimize tracer uptake in tumor tissue. If the patient does not follow the instructions, it may increase tracer uptake in normal tissue which may have a negative impact on the interpretation of the images, which could lead to a delayed cancer diagnosis.^{3,48} The ¹⁸F-fluoride PET/CT examination requires the patient to follow instructions from the nursing staff to secure high image

quality, i.e. intense tracer activity in the urinary bladder could have a negative impact on the interpretation of images of the pelvis.^{7,8,10}

Health-related quality of life

HRQoL has a wide variety of definitions.^{49,50} According to the World Health Organization, it is the state of physical, emotional and social well-being.⁵¹ There is a correlation between patient satisfaction and self-reported HRQoL. Patients with high satisfaction scores also had better HRQoL.^{52,53} If the patient's HRQoL increased during cancer treatment did satisfaction with care increase as well.⁵³ In some studies, a correlation might not be found at all. However, even when no correlations between clinical variables and HRQoL are found it is a valuable measure that offers information about the patient.⁵⁰ Low HRQoL could mean low physical and emotional well-being, which could potentially have a negative impact on the patient's satisfaction with care, interactions with nursing staff and the ability to follow the required instructions during the PET/CT examination.

Perceived stress and physical activity

The cancer diagnosis may affect different aspects of daily life such as the ability to carry out physical activity, and many patients may also experience cancer-related fatigue to varying degrees. However, it has been found that physical activity has a positive effect on the level of experienced cancer-related fatigue.^{54,55} Perceived stress and emotional well-being were associated with intolerance of uncertainty and perceived ambiguity in relations to the lung cancer.⁵⁶ Patients who experience low physical activity or high levels of perceived stress may be in a physical and emotional state that could aggravate the PET/CT examination procedure which requires cooperation from the patient during procedure. A possible cancer diagnosis may generate high levels of distress and a decreased quality of life. The reduction of distress after a benign diagnosis may indicate the necessity of a quick diagnostic examination.⁵⁷

Rationale for the current thesis

Oncological patients that are referred for a PET/CT examination have a suspected or known cancer diagnosis. This is something that may negatively affect various aspects of daily life for these patients, such as physical and psychological well-being. This in turn may negatively affect the patient's experience with the PET/CT examination and satisfaction with care. The patient may be dependent on the results of the PET/CT examination for the diagnosis, treatment and prognosis of their known or suspected disease,

which could raise all sorts of thoughts and feelings. The PET/CT examination is dependent on the patients understanding and following instructions before the examination and instructions from the nursing staff during the examination procedure in order to ensure high image quality. Low image quality may have a negative effect on the interpretation of the images and could thereby lead to a delayed diagnosis or start of a cancer treatment. An increased knowledge about the patients experience and satisfaction with care in connection with PET/CT examinations would thus, be useful to help find ways to improve patient information and care before and during the PET/CT examination procedure and could potentially increase patient satisfaction and their ability to follow the instructions from nursing staff. This in turn, may help ensure a high image quality.

Aims

The overall aim for this thesis was to investigate patients' experiences with a PET/CT examination, satisfaction with care provided in connection to the examination and whether web-based information can improve satisfaction with care and image quality, compared to standard care. An additional aim was to explore how satisfaction with care and image quality are associated with HRQoL and perceived stress.

The specific aims of papers I to IV were:

- I To investigate the patients' knowledge about and experience of the ^{18}F -FDG PET/CT examination. An additional aim was to investigate the self-reported feelings of perceived stress, the level of physical activity, and the experienced HRQoL and to find out if this was related to how the patients experienced the examination.
- II To investigate patients' previous knowledge, satisfaction, and experience regarding an ^{18}F -fluoride PET/CT examination and to explore whether discomfort or pain during the examination negatively affects image quality. A secondary aim was to explore whether patients' HRQoL is associated with their satisfaction and experience regarding the examination.
- III To explore how patients with head and neck cancer experienced undergoing an ^{18}F -FDG PET/CT examination in a fixation mask.
- IV To investigate what effect web-based patient information had on patients' satisfaction with care during an ^{18}F -FDG PET/CT examination, their knowledge about the examination and image quality, compared with standard care and to explore how age, gender, perceived stress, HRQoL and knowledge are associated to satisfaction with care and the image quality of an ^{18}F -FDG PET/CT examination.

Materials and methods

Study design

Study I and II were quantitative studies using a cross-sectional descriptive design. Study III was a qualitative study using a phenomenological methodology. Study IV was a randomized controlled trial.

Table 1. *Summary of study design, participants, data collection and data analysis.*

Study	Design	Participants	Data collection	Data analysis
I	Cross-sectional descriptive	Patients with known or suspected malignancy scheduled for an ^{18}F -FDG PET/CT examination	Questionnaires	Descriptive and analytic statistics
II	Cross-sectional descriptive	Patients with known or suspected bone metastases scheduled for an ^{18}F -fluoride PET/CT examination	Questionnaires and image quality assessment	Descriptive and analytic statistics
III	Qualitative	Patients with head and neck cancer scheduled for an ^{18}F -FDG PET/CT examination in a fixation mask	Interviews	Phenomenological methodology
IV	Randomized controlled trial	Patients with known or suspected malignancy scheduled for an ^{18}F -FDG PET/CT examination	Questionnaires and image quality assessment	Descriptive and analytic statistics

Study settings

Study I, III and IV were conducted at the Department of Nuclear Medicine at Uppsala University Hospital. Study II was conducted at the PET-Centre at Uppsala University Hospital. All examinations were conducted according to local regulations.¹⁹

PET/CT examinations

The PET/CT examinations in study I, III and IV were performed on a Discovery VCT (GE, Healthcare) with 64 slice CT and the PET/CT examinations in study II on a Discovery ST PET/CT Scanner (GE, Healthcare).

Study I and IV

The patient is instructed to fast for six hours and to drink 0.5-1 liter of tap water prior to the ¹⁸F-FDG PET/CT examination. Upon arrival, the patient is given information about the examination procedure and taken to a warm resting place. The patient is instructed to remain silent and recumbent during the intravenous injection of 4Mbc per kilogram of bodyweight of ¹⁸F-FDG and during the subsequent one-hour uptake phase. The patient is also instructed to drink 0.5 liter tap water after 30 minutes and to empty the bladder immediately prior to the PET/CT scanner acquisition. The ¹⁸F-FDG PET/CT scanner acquisition is carried out with the patients positioned supine on the stretcher of the PET/CT scanner with arms elevated over the head. At first, a low-dose scan for attenuation correction is performed. Then a whole-body scan is conducted by moving the patient through the scanner tunnel in steps (bed positions). The scan was acquired from the middle of the patient's thigh to the jaw angle or top of the skull. The bed position time was three minutes in 3-dimensional mode. In study IV a diagnostic CT with intravenous contrast enhancement was carried out after the whole-body scan. Total PET/CT scanner time was approximately 25-30 minutes and total examination time two hours.

Study II

The ¹⁸F-fluoride PET/CT examination does not require any patient preparations and during the subsequent uptake phase, the patient is instructed to drink a lot and to empty the bladder often, especially just prior to the PET/CT scanner acquisition. The ¹⁸F-fluoride PET/CT scanner acquisition was executed one hour after the patient received an intravenous injection of 3MBq ¹⁸F-fluoride per kilogram of bodyweight. The patients were positioned supine with arms elevated over the head. The PET/CT examination consists of a low-dose CT scan for attenuation correction, followed by a whole-body scan by moving the patient through the PET/CT scanner in steps (bed positions). The scan was acquired from the middle of the patient's thigh

to the top of the skull. The time per bed position was two minutes in 3-dimensional mode. In total, PET/CT scanner acquisition time was approximately 20 minutes and total examination time 1.5 hours.

Study III

The ^{18}F -FDG PET/CT examination in a fixation mask requires the patient to fast for six hours and to drink 0.5-1 liter of tap water prior to the examination. Upon arrival, the patient is taken to a warm resting place and instructed to be silent and to relax for 15 minutes before the intravenous injection of 4Mbcq ^{18}F -FDG per kilogram of bodyweight and also during the subsequent one-hour uptake phase between injection and PET/CT acquisition. The ^{18}F -FDG PET/CT examination in a fixation mask is carried out with the patient positioned supine in the PET/CT scanner, and the fixation mask is placed on the patient's face in the same way as during radiation treatment. The PET/CT acquisition consists of a low-dose scan for attenuation correction followed by a PET scan covering the liver to the top of the skull by moving the patient stepwise (bed positions) through the PET/CT scanner. The time per bed position was three minutes in 3-dimensional mode. Finally a diagnostic CT examination with intravenous iodine contrast enhancement was conducted covering the same body region. In total, PET/CT scanner acquisition time was approximately 25 minutes and total examination time two hours.

Participants

Study I

The study was conducted between October 2011 and April 2012. The inclusion criterion was consecutive patients who were scheduled for a standard whole-body ^{18}F -FDG PET/CT examination without intravenous iodine contrast and who not had the examination before. The patients were 18 years or older and fluent in Swedish, and the reason for referral was known or suspected malignancy.

Study II

The enrollment period took place from November 2011 to April 2013. The inclusion criterion was consecutive patients who were scheduled for an ^{18}F -fluoride PET/CT examination. The patients had a histopathologic diagnosis of prostate cancer with known or suspected bone metastases and were fluent in Swedish.

Study III

Patients who were scheduled for an ^{18}F -FDG PET/CT examination in a fixation mask for the first time were conveniently enrolled from February 2012 to August 2015. The patients had known or suspected oropharynx and oral cancer, were 18 years or older and could speak and understand Swedish. Patients who required anxiolytic medication just prior to the examination were excluded, since this could potentially influence their experience of the examination.

Study IV

The inclusion period took place between October 2015 and December 2016. Patients who were scheduled for a standard whole-body ^{18}F -FDG PET/CT examination with or without intravenous iodine contrast and not had the examination before were approached. The reason for referral was known or suspected malignancy and the patients were 18 years or older and fluent in Swedish. Patients were excluded if they were scheduled for the ^{18}F -FDG PET/CT examination less than seven days (October 2015-June 2016) or less than five days (July 2016-December 2016) after the notice for the examination was sent out.

Procedure study I-III

Study I and II

Patients were asked to participate in the study after completion of the PET/CT examination when oral and written information about the study were given to the patient by the author (CA) or the nursing staff that carried out the PET/CT examination. If the patient agreed to participate, he or she received a questionnaire. It could be completed at the department at which the PET/CT examination was performed, or the patient could take it home and send it back in a self-addressed, stamped envelope. A reminder and a copy of the questionnaire were sent to the participants if no reply was received within three weeks.

Study III

Patients were asked to participate in the study by the author (CA) after the ^{18}F -FDG PET/CT examination in a fixation mask was completed. The patient received oral and written information about the study and if the patient agreed to participate, a conversational interview was conducted either immediately (n=6) or within one week (n=3).

Intervention and procedure study IV

The patients were assessed for eligibility by the nursing staff at the nuclear medicine department, who reviewed all incoming referrals. Patients who were considered eligible received written information about the study together with the notice for the ^{18}F -FDG PET/CT examination. The patients were contacted by phone after a few days by the author (CA), who provided oral information about the study. If the patients agreed to participate and to send back the signed consent, they were randomized to either the intervention group or the standard care group. The patients received an e-mail regarding which group they would belong to and information that they could contact the first author if they had any questions. After the ^{18}F -FDG PET/CT examination was completed, the patients received a questionnaire by post together with a stamped, self-addressed envelope. A reminder and a copy of the questionnaire were sent to the participant if no reply was received within two weeks.

Standard care and the web-based information intervention

All patients received information about the ^{18}F -FDG PET/CT examination according to standard care which consists of written information together with the notice for the examination, in total two pages. In addition to this information, patients in the intervention group had access through a learning management system (LMS) to a slideshow with photos, pictures and a voice-over explaining how an ^{18}F -FDG PET/CT examination is conducted, the reason for the pre-examination instructions and instructions during the examination procedure, what happens after the examination and how the patients would receive information about the results of the examination. The patients could also read the text online and there was a module with common questions and answers regarding the ^{18}F -FDG PET/CT examination. All materials were designed by researchers within the project and checked by a radiologist and a physicist with extensive ^{18}F -FDG PET/CT experience. The material was also reviewed by five patients who were not included in the study; minor corrections were made based on their opinions.

Power analysis and randomization

A power analysis was conducted and it estimated that one hundred patients in each group would give 80% power to discover a mean difference of 1.8 (SD 4.8) between the groups, with regard to overall satisfaction (see Data collection – Patient satisfaction below). Randomization was carried out according to Efron's biased coin design⁵⁸ by a person not belonging to the research group.

Data collection

Information about diagnosis was retrieved from the referral in study I, II and IV and about age, gender in study IV.

Table 2. *Questionnaires used in study I, II and IV.*

Study	Questionnaire
I	Demographics* Satisfaction* PEQ29 Knowledge* Discomfort* EORTC-QLQ-C30 Perceived stress* Physical activity*
II	Demographics* Satisfaction* PEQ29 Knowledge* Discomfort* EORTC-QLQ-C30 EORTC-QLQ-PR25
IV	Demographics* Satisfaction* PEQ29 Knowledge* Discomfort* EORTC-QLQ-C30 PSS-10 Web-based information*

*Project-specific questions

PEQ29= Patient experience questionnaire (Five questions used in study I, II and IV)

EORTC-QLQ-C30= European organization for research and treatment of cancer (EORTC) quality of life questionnaire-core 30

EORTC-QLQ-PR25= quality of life questionnaire-prostate cancer module

PSS-10= Perceived stress scale-10 item

Patient demographics

Data regarding civil status, level of education, occupation and monthly income were collected with project-specific questions in study I, II and IV.

Patient satisfaction

In study I, II and IV two questions were regarding patient satisfaction with the information about the examination and one question was regarding satisfaction with interactions with the nursing staff. These three questions had a five-point scale (0 = “not at all” to 4 = “to a very high degree”). Study IV included an additional question about patient satisfaction concerning the information about how the patient would receive the results of the ¹⁸F-FDG PET/CT examination. It had a five-point scale (0 = “not at all” to 4 = “to a very high degree”). All these questions were project-specific (Appendix 1, 2 and 4). In study I, II and IV, five questions were from the Patient Experience Questionnaire (PEQ29).⁵⁹ They were regarding patient satisfaction with interactions with the nursing staff, including their communication and professional skills, and the patient’s overall impression of the hospital. They had a five-point scale (0 = “not at all” to 4 = “to a very high degree”). The eight questions in study I were used for the sum variable measuring overall patient satisfaction with the ¹⁸F-FDG PET/CT examination used for the power analysis in study IV.

Patient knowledge and discomfort

Patient knowledge and discomfort were assessed with project-specific questions (study I, II and IV; Appendix 1, 2 and 4). Two questions were regarding participants’ knowledge about the PET/CT examination. They had a four-point scale (0 = “not at all” to 3 = “quite a lot”). Three questions were regarding the participants’ discomfort during the PET/CT examination. They had a four- or five-point scale. One question was about how exhausting the examination was (0 = “not at all exhausting” to 3 = “very much exhausting”). One question asked if the examination corresponded with the participant’s expectations (0 = “much easier” to 4 = “much worse”). One question was about if the participant felt trapped during the examination (0 = “not at all trapped” to 3 = “very much trapped”). It was also possible for the patient to add free-text comments regarding what they considered as exhausting during the PET/CT examination.

Health-related quality of life

In study I, II and IV the European Organization for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire-Core 30 (QLQ-C30) was used to investigate HRQoL. QLQ-C30 was transformed to five function scales, nine symptom scales and a global quality of life scale. All scales were linearly transformed into a scale of 0-100, with higher scores reflecting more symptoms, higher level of functioning, and better global health status/quality of life.⁶⁰ In addition study II included the prostate cancer-specific module

QLQ-PR25, which was transformed to one function and five symptom scales.⁶¹

Perceived stress

In study I, the level of perceived stress was assessed by three project-specific questions (Appendix 1). They had a five-point scale (0 = “almost never” to 4 = “almost always”). In study IV, the Swedish 10-item version of Perceived Stress Scale (PSS-10)⁶² was used to investigate patients’ level of perceived stress (Appendix 4). The questions has a four-point scale (0 = “never” to 3 = “very often”). The PSS score is obtained by summing all items after reversing the scores on the four positive items.⁶³

Physical activity

In study I three questions were regarding physical activity levels using a six- or seven point scale. One question was about daily activity (0 = “sitting still” to 5 = “heavy labor”). One question was about the frequency of walking or cycling (0 = “almost never” to 5 = “2 hour per day”). One question was about the frequency of other exercise (0 = “almost never” to “6 = 5 hour per week”). All questions were project-specific (Appendix 1).

Web-based information – utilization, satisfaction and perceived benefits

Patients in the intervention group were asked 15 questions on the usability of and satisfaction with the web-based information, and whether it helped them prepare for and undergo the ¹⁸F-FDG PET/CT examination. The questions had a three-, four- or five-point scale and were project-specific questions (Appendix 5). Information about which of the patients in the intervention group used the web-based information and the number of times was retrieved from the LMS.

Due to lack of time were some of the questions in the questionnaires not analyzed. These were in study I, II and IV regarding the patients number of school years, occupational identity and use of tobacco. In study I and II regarding the patient’s length and weight, information about how the patient was notified about their time for appointment for the PET/CT examination and proposal for change. In study I if the patient had any chronic diseases and if the patients family had any serious diseases. In study II and IV regarding the patients’ occupation. In study IV if the patient had searched for information elsewhere, if so where and what was considered to be stressful during the examination procedure (Appendix 1, 2 and 4).

Image quality assessment

Study II

A form with a three-point scale designed for the study was used to assess the occurrence of image artifacts such as; lesion conspicuity, extent of image impairment, overall diagnostic accuracy and number of pathological findings (suspected bone metastases; Appendix 3). The assessment was done by a senior radiologist with extensive PET/CT experience.

Study IV

A form with a two-, or three-point scale designed for the study was used to assess the presence of image defects that were considered to affect the image quality negatively (Appendix 6) such as; physiological uptake in larynx (vocal cords), degree of muscle uptake, presence of activated brown fat, motion artifacts, amount of bladder activity, overall diagnostic accuracy and variant of uptake (malignant or benign findings). The assessment was done blinded with respect to whether the patient belonged to the intervention group or standard care group by an experienced nuclear medicine specialist with extensive PET/CT experience.

Interviews – Patient experiences of ^{18}F -FDG PET/CT in a fixation mask

Study III

Face to-face interviews were conducted in a private room in the department by the author (CA), a nurse at the nuclear medicine department. A conscious effort was made to avoid being influenced by pre-existing biases about the investigated phenomena. The interviews took up to 30 minutes and started with the open-ended question; “You have now gone through a PET/CT examination in a fixation mask. How did you experience the examination?” Follow-up questions were asked to ensure the best possible description of the investigated phenomena. The interviews were conducted in Swedish, tape-recorded and then transcribed verbatim. The quotes were later translated to English.

Data analysis

Study I, II and IV

Data were analyzed using Statistical Package for Social Sciences version 20.0 (study I and II) and version 24.0 (study IV).

Descriptive statistics were used regarding demographics and patients responses to questions about their knowledge, satisfaction and discomfort with regard to PET/CT examinations and the utilization, satisfaction and perceived benefits with the web-based information. The free-text comments were categorized.

Table 3. *Analytic statistics.*

Study	Analysis
I	Spearman's correlations coefficient
II	Mann Whitney <i>U</i> test Spearman's correlations coefficient
IV	T-test Mann-Whitney <i>U</i> test Chi-square test Spearman's correlations coefficient Cramer's V

Study I

The Spearman's correlations coefficient was used to investigate whether patients' knowledge about and experience of the ¹⁸F-FDG PET/CT examination were correlated with perceived stress, physical activity and HRQoL. The items of HRQoL were restricted to the ones most likely to influence the experience of the ¹⁸F-FDG PET/CT examination such as: functional scales, dyspnea and pain. The level of statistical significance was set at $p < 0.01-0.05$. The three questions regarding perceived stress and physical activity were summarized to one variable each; with higher scores reflecting more perceived stress and more physical activity. The summarized variables were used in the correlations analyses.

Study II

The Mann-Whitney *U* test was used to analyze differences between patients who had undergone a PET/CT examination before and those who were undergoing a PET/CT examination for the first time. The Spearman's correlations coefficient was used to investigate how previous knowledge, satisfaction and experience regarding the examination correlated with HRQoL and how previous knowledge correlated with satisfaction and experience regarding the examination. The items of HRQoL were restricted to the ones most likely to influence the experience of the examination such as; functional scales, dyspnea, fatigue and pain. The level of statistical significance was set at $p < 0.01$ due to the large number of analyses. A descriptive analysis was done to investigate the relationship between image quality and patients' previous knowledge of the examination, and between image quality and patients' experience of discomfort during the examination.

Study IV

Analyses were done by intention to treat. All analyses were also done per protocol comparing only those in the intervention group that used the web-based information with the standard care group. The T-test was used to analyze differences between mean overall satisfaction in the intervention group and standard care group. The Mann-Whitney *U* test was used to analyze differences between the intervention group and standard care group regarding satisfaction single variables, knowledge and experienced discomfort. The chi-square test was used to analyze differences between the intervention group and standard care group regarding image quality. The Spearman's correlations coefficient was used for data on ordinal level and Cramer's *V* for data on nominal level to investigate how age, gender, HRQoL, perceived stress and knowledge correlated with satisfaction and image quality. The level of statistical significance was set at $p < 0.01$ due to the large number of analyses. Mann-Whitney *U* test (continuous and ordinal variables) or Chi-square test (categorical variables) were used to analyze differences in background data between intervention group and standard care group, between those who used the web-based information and those who did not, and between participants and those who declined participation.

Study III

The analysis was done by author (CA) in close cooperation during all the steps of the process with the researchers within the project. The interviews were read thoroughly and analyzed separately. The sentences were grouped under the four fundamental existentials: lived space, lived body, lived time and lived relation and then changed from the spoken language to descriptions of what had been said. The descriptions were summarized and categorized according to phases during the examination procedure as follows: uptake phase, the PET/CT scanner and the fixation mask, since each of these phases requires patient cooperation and understanding. The categories were compared and then combined, to procedure a description of the lived world during the PET/CT examination in a fixation mask.

Ethical considerations

Study I, II, III, IV

All participants received written and oral information about the studies by the first author or the nursing staff that carried out the PET/CT examination. All participants signed a written informed consent. It was clarified that participation in the studies was voluntary and that patients could discontinue their participation at any time if they so wished, without affecting their care.

A telephone number was provided if the participants had any questions regarding the studies. All collected data were treated confidentially. The studies were approved by the regional ethics review board in Uppsala, Sweden (approvals 2011/277, 2014/549 and 2014/549/1).

Answering questionnaires about the experience with the PET/CT examination, HRQoL, perceived stress and physical activity and participating in interviews regarding experiences with the ^{18}F -FDG PET/CT examination in a fixation mask may raise unpleasant thoughts and feelings for some patients. It must also be taken into consideration that some patients may have expressed their willingness to participate because they were asked for the participation of the nursing staff that carried out the PET/CT examination. However, cancer patients are often willing to participate in research studies, mainly due to the possibility of receiving the best treatment for their disease or because participation results in benefits for other patients.⁶⁴ These patients may have had positive perceptions about expressing their opinions, thoughts and feelings with regard to the PET/CT examination and the fact that this could result in benefits for other patients or for themselves, if they go through the examination again in the future.

Results

Patient demographics

Table 4. *Demographic and clinical characteristics of patients in study I, II and IV.*

	Study I (n=169)	Study II (n=46)	Study IV		
			Standard care group (n=73)	Intervention Group	
				Used the intervention (n=54)	Did not use the interven- tion (n=21)
	Mean (range) n (%)	Mean (range) n (%)	Mean (range) n (%)	Mean (range) n (%)	Mean (range) n (%)
Age	64 (19-92)	69 (59-83)	63 (24-84)	64 (26-80)	64 (30-80)
Gender					
Male	90 (53)	46 (100)	34 (47)	30 (56)	10 (48)
Female	79 (47)	0	39 (53)	24 (44)	11 (52)
Education					
Compulsory school	65 (39)	16 (36)	13 (20)	7 (13)	7 (33)
Upper se- condary school	63 (38)	13 (28)	29 (45)	21 (39)	6 (29)
University 0-4 years	27 (16)	5 (11)	15 (23)	11 (20)	3 (14)
University > 4 years	13 (8)	11 (24)	7 (11)	9 (17)	1 (5)
Known or suspected cancer diag- nosis					
Lung cancer	62 (37)	0	25 (34)	23 (43)	7 (33)
Colorectal cancer	30 (18)	0	5 (7)	15 (28)	2 (10)
Ovarian cancer	10 (6)	0	9 (12)	5 (9)	4 (19)
Other	67 (40)	0	34 (47)	11 (20)	8 (38)
Prostate cancer	0	46 (100)	0	0	0

Study I

There were 189 of 198 approached patients who agreed to participate. Of these, 20 patients completed the questionnaire at the nuclear medicine department and 169 patients took the questionnaire home: of these, 149 questionnaires were returned by post. The response rate was thus 89%, or 169 participants. There were 90 men and 89 women and the mean age was 64 years (range 19-92 years). The most common known or suspected diagnosis was lung cancer (Table 4). The majority (n=162) were outpatients.

Study II

There were 48 of 50 approached patients who agreed to participate. Of these, 6 patients completed the questionnaire at the PET-Centre. Forty-two patients took the questionnaire home, of which 40 questionnaires were returned by post. The response rate was thus 96%, or 46 participants. The mean age was 69 years (range 59-83 years). Six patients had undergone an ¹⁸F-fluoride PET/CT examination before and 19 had undergone another PET/CT examination. According to the referral, some patients had previously been diagnosed with known (n=10) or suspected (n=9) bone metastasis in another imaging examination (CT or MRI). All patients were outpatients.

Study III

Nine patients (7 men and 2 women) were included in the study. The participants' ages ranged between 48 and 75 years. Reasons for referral were investigation of tumor extent and diagnosis of regional and distant metastasis (n=3), investigation of tumor extent and radiation treatment planning (n=2), radiation treatment planning (n=3), and verification of tonsil cancer diagnosis (n=1). There were 11 patients who declined to participate and two patients were excluded because they required anxiolytic medication prior to the ¹⁸F-FDG PET/CT in a fixation mask examination. All patients were outpatients.

Study IV

There were 148 of 393 approached patients who agreed to participate and were randomly assigned to the intervention group (n=75) and standard care group (n=73). The response rate was 88%, or 130 returned questionnaires (intervention group n=66 and standard care group n=64). See flowchart (Appendix 7). The most common known or suspected diagnosis was lung cancer (Table 4). All patients were outpatients.

Web-based intervention

There were no statistically significant differences between the intervention group and the standard care group with regard to patient demographics, satisfaction, discomfort, knowledge, image quality, perceived stress or HRQoL. However, there was a statistically significant difference with regard to the distribution of diagnosis (Chi-square test 11.2, $p=0.01$). There was a statistically difference between patients who had agreed to participate in the study and those who declined with regard to age ($p=0.001$) and between patients in the intervention group that used the web-based information and those who did not use it with regard to level of education ($p=0.032$).

Patient satisfaction

The results revealed that patients were highly satisfied with care, both with regard to overall satisfaction (intervention group mean = 28.4, standard care group mean = 28.8) and single satisfaction variables for the intervention group and standard care group. The lowest scores were regarding information about how patients would be notified of ^{18}F -FDG-PET/CT examination results: 15% of patients in the intervention group and 17% of patients in the standard care group were “not at all” or “to a low degree” satisfied. The highest scores were regarding whether the patient felt confident in the professional skills of the nursing staff to “a very high degree”: 52% of patients in the intervention group and 59% of patients in the standard care group gave that response.

Image quality

The image quality was assessed as high for all patients. However, the number of detected image quality defects was somewhat higher in the standard care group compared to intervention group with regard to physical uptake in larynx ($n=44$ vs $n=38$), abnormal bladder activity ($n=16$ vs $n=11$), activated brown fat ($n=4$ vs $n=0$) and motion artifacts ($n=9$ vs $n=6$). With regard to muscle uptake, the number of detected image defects was higher in the intervention group than the standard care group ($n=18$ vs $n=16$). More patients had malignant uptake than those that did not have suspicious malignant uptake about 2/3 of patients in the intervention group and about 1/2 of patients in the standard care group.

Web-based information

There were 54 of the 75 patients, or 72% in the intervention group who used the web-based information and logged in to the system between 1 to 6 times. The results regarding the important aspects of usability, satisfaction and perceived benefits with the web-based information are shown (Table 5).

Table 5. *Results important aspects of usability, satisfaction and perceived benefits with the web-based information (n=49 of 54, 89%).*

Question	n (%)
How did you think it was to navigate in the web-portal and to use its features?	
Very easy	16 (33)
Pretty easy	29 (59)
Quite difficult	4 (8)
Very difficult	1 (2)
Was the content presented so that it was easy to understand?	
Not at all	0
To a small extent	0
To some extent	8 (16)
To a high extent	35 (71)
To a very high extent	6 (12)
What did you think about the time when you got access to the web-based information?	
Too, early it should have been presented at a time closer to the examination	0
It was right in time	43 (88)
Too late, I had wanted access to the web-based information earlier	6 (12)
How much benefit did you have from the web-based information in the following respects?	
Reduced worry about the examination	
I didn't worry	17 (35)
No use at all	1 (2)
A little use	7 (14)
Quite a lot use	18 (37)
Much use	4 (8)
The preparations before the examination	
No use at all	0
A little use	14 (29)
Quite a lot use	26 (53)
Much use	7 (14)
To undergo the examination	
No use at all	1 (2)
A little use	10 (20)
Quite a lot use	28 (57)
Much use	8 (16)

Would you recommend the web-based information to someone else who will undergo the same PET/CT examination as you?

Yes, absolutely	28 (57)
Yes, I think so	20 (41)
No, I do not think so	0
No, absolutely not	0

Patient satisfaction

Study I and II

The results of study I and II reveal that the patients were generally satisfied with care provided by the nursing staff in connection with the PET/CT examination. The lowest scores in study I were regarding communication with the nursing staff: 45% of patients were “not at all”, “to a low degree” or “some” satisfied. There were also relatively low scores regarding the information the patient received about the ^{18}F -FDG PET/CT examination prior to the examination: 31% of patients were “not at all”, “to a low degree” or “some” satisfied. However, the majority (57-63%) of patients were satisfied “to a very high degree” with the interaction and professional skills of the nursing staff. In study II, the majority of patients were satisfied “to a very high degree” (52-70%) with the information upon arrival for the ^{18}F -fluoride PET/CT examination, the interaction, communication and professional skills of the nursing staff. The lowest satisfaction score was obtained regarding the information patients received prior to the ^{18}F -fluoride PET/CT examination: 22% of patients were satisfied “to a low” or “some” degree.

Patient knowledge and discomfort

Study I, II and IV

As many as, 52% of patients in study I did not know at all what an ^{18}F -FDG PET/CT examination was before undergoing the examination, and 46% of patients did not know at all how the examination would be conducted prior to the exam. In study II, 26% of patients did not know at all what an ^{18}F -fluoride PET/CT examination was before the examination, and 24% did not know how the ^{18}F -fluoride PET/CT examination would be conducted. In study IV, patients’ knowledge about what an ^{18}F -FDG PET/CT examination was prior to the examination was similar between patients in the intervention group and standard care group: 38% and 36% respectively did not know at

all. However, there was a larger difference between patients in the intervention group and standard care group regarding how the ^{18}F -FDG PET/CT examination would be conducted: 33% vs 44% did not know that at all.

In study I, 37% of patients found that the ^{18}F -FDG PET/CT examination to be exhausting to varying degrees and 28% of patients felt “some” or “much” trapped during the examination. In study II, 27% of patients thought the ^{18}F -fluoride PET/CT examination was exhausting to a varying degree and 27% felt trapped during the examination to “some” degree. In study IV, 40% of patients in the intervention group and 45% of the patients in standard care group considered the ^{18}F -FDG PET/CT examination to be exhausting to varying degrees. There were fewer patients in the standard care group (29%) than patients in the intervention group (41%) that felt trapped during the examination.

In study I, 38 patients wrote comments about what they found to be exhausting during the ^{18}F -FDG PET/CT examination. Of these, 24 patients commented on physical factors, such as, the position of the arms while the patient was in the PET/CT scanner or back pain. Eleven patients commented on emotional factors, such as, insecurity or loneliness. Three patients commented on water intake. In study II, were 11 patients wrote comments on what they considered to be exhausting during the ^{18}F -fluoride PET/CT examination. Nine patients commented on physical factors, such as, the arms position of the arms while in the PET/CT scanner and two patients commented on emotional factors, such as, distress. In study IV, 38 patients considered the fixed positioning of the body in the PET/CT to be most exhausting, followed by the wait for the results of the ^{18}F -FDG PET/CT examination by 9 patients.

Health-related quality of life

Study I, II and IV

The results regarding HRQoL in study I and IV revealed the global health status to be relatively low, study I: mean 57. Study IV intervention group: mean 61; standard care group: mean 63. The functional scale scores are higher than 50 for all these groups. In study I role functioning had the lowest score (mean 66). In study IV, emotional functioning had the lowest score in the intervention group (mean 71) and role functioning had the lowest score in the standard care group (mean 66). Symptom and single-items scores were lower than 50. In both study I and IV, fatigue had the highest score. In study I the mean was 40 and in study IV the mean was 32 in both the intervention group and the standard care group. In study II, HRQoL was relatively high

(mean 74). Functional scale scores were higher than 50. Emotional functioning had the lowest score (mean 87). Symptom scale and single-item scores were lower than 50. Insomnia had the highest score (mean 21).

Perceived stress

Study I and IV

In study I the level of perceived stress was relatively low since the mean score was 4 on the summary scale, which had a maximum score of 10. In study IV, the level of perceived stress was slightly high in both the intervention group (mean 16) and standard care group (mean 15) in comparison with a Swedish prescriptive population ⁶². Higher scores represented more perceived stress in both studies.

Physical activity

Study I

The level of physical activity among the participants in study I was relatively low with a mean score of 4 on the summary scale which had a maximum score of 14. Higher scores represented more physical activity.

Image quality

Study II

The image quality assessment found an overall high image quality. All images were without artifacts except for one patient whose images had small artifacts. Lesion conspicuity was without fault for all patients and all images and anatomic regions were fully diagnostic. Nineteen patients did not have any bone metastases on the ¹⁸F-fluoride PET/CT images, 21 patients had solitary (1-5) metastases, and 6 patients had many bone metastases (>6) on the ¹⁸F-fluoride PET/CT examination. There were no differences regarding image quality and patients' previous knowledge, experienced discomfort or pain.

Patients experiences of ^{18}F -FDG PET/CT in a fixation mask

Study III

The lifeworld of the patients was suddenly altered during the ^{18}F -FDG PET/CT examination in a fixation mask, and patients' thoughts and feelings varied. Three areas were identified that represent different phases of the examination procedure each requiring in their own ways understanding and cooperation of the patient: the uptake phase, PET/CT scanner and fixation mask. These are presented in relation to the four lifeworld existentials: lived space, lived body, lived time and lived relation (Table 6).

Table 6. *Summary of findings regarding patients with head and neck cancer experiences of an ^{18}F -FDG PET/CT examination in a fixation mask.*

	Lived space	Lived body	Lived time	Lived relation
Uptake phase	This was an unknown environment. Some patients thought it was relaxing while other were uneasy.	The lived body was affected. To lie still and not be able to move as they wanted was of some patients experienced as unpleasant.	The sense of time varied among the patients. Some thought it slowed down or almost stood still.	Some patients felt deserted by the nursing staff. A sense of loneliness occurred. They wanted to know that they not were forgotten.
PET/CT scanner	Some patients experienced it as unpleasant but still accepted.	The positioning of the patient did for some patients result in a negative awareness of the body.		Satisfaction with care varied. Patients who thought themselves well-informed were more satisfied.
Fixation mask	The lived space was restricted. The patients were unable to get away from the mask.	It was warm, uncomfortable and physically unpleasant.	The perception of time varied. It was hard to know how much time that had passed.	It was hard or impossible for the patient to communicate. The patients would have wanted reassurance that they not were forgotten

The essence of the patients experienced lifeworld during the ^{18}F -FDG PET/CT examination was a determination to maintain composure and to go through the examination procedure no matter what.

“For me it’s just a question of endurance. I know why I’m here and the better examination and instruments they have to assess me the better results they get. There is no alternative. It’s just a question of endurance” (Pat 2).

Correlations

Study I

There were a number of statistically significant correlations between the patients’ experiences with the ^{18}F -FDG PET/CT examination and HRQoL, and the level of perceived stress and physical activity, such as: low patient satisfaction with interactions with the nursing staff correlated with worse dyspnea and fatigue ($p < 0.01-0.05$); high patient discomfort, especially how exhausting the examination was, correlated with worse dyspnea, fatigue and pain ($p < 0.05-0.01$); and experienced claustrophobia correlated with higher levels of perceived stress ($p < 0.05$).

Study II

There were no differences between patients had undergone a PET/CT examination before and patients undergoing the examination for the first time. There was also no statistically significant correlation between patient experience and satisfaction regarding the ^{18}F -fluoride PET/CT examination and HRQoL.

Study IV

There were no statistically significant correlations between image quality and age, gender, perceived stress, HRQoL or knowledge, or between patient satisfaction and perceived stress. However, there were some correlations between patient satisfaction and HRQoL, such as worse fatigue and insomnia and satisfaction with how the patients would receive the results of the ^{18}F -FDG PET/CT examination ($p < 0.01$).

Discussion

The overall aim for this thesis was to investigate patients' experiences with a PET/CT examination, satisfaction with care provided in connection to the examination and whether web-based information can improve satisfaction with care and image quality, compared to standard care. The findings showed that patient satisfaction was high with regard to both overall satisfaction and single satisfaction variables in the intervention group and standard care group. There were no statistically significant differences between the intervention group and standard care group. The image quality was high in both groups. However, descriptive statistics revealed a slightly higher number of detected image quality defects in the standard care group compared to the intervention group. The web-based information helped the patients in the intervention group to prepare before and undergo the ^{18}F -FDG PET/CT examination. However, the results are limited due to the lack of power of the primary outcome overall satisfaction due to early determination of the recruitment of patients and 28% of the patients did use the web-based intervention.

Web-based information

Patient satisfaction with care was high in both the intervention group and standard care group. The lowest scores were regarding the information about how the patients would receive information about the results of the ^{18}F -FDG PET/CT examination. This is partly similar to Grilo *et al.* who found that it was the worry about the results of the ^{18}F -FDG PET/CT that was the most common cause of anxiety with the patient.³¹ The nursing staff that carries out the PET/CT examination should be aware of this and try to find ways to make sure that the patient is satisfied with the information about how they will receive the results. In the present study there were no statistically significant differences between the intervention group and standard care group. However, the web-based information helped the patients to prepare before and to undergo the ^{18}F -FDG PET/CT examination, it also helped to decrease their worry before the examination. This is similar to findings by Ketelaars *et al.* in their study regarding the use of video information to reduce patient anxiety before colposcopy. They did not find any effects of the intervention but the patients were satisfied with the video information and it helped to de-

crease the anxiety with the patients especially those who were extremely anxious.³⁹ The web-based information support system regarding their disease was appreciated by patients with neuroendocrine but it did not have any positive effects on satisfaction with information.⁶⁵ It is thereby indicated that web-based information may be of value for the patients in future healthcare. However, it needs to be investigated further how to best optimize the content of web-based information and it is suggested that a group of patients take part in the construction. The image quality was deemed as high for all patients even though there was a small increase of defects in the standard care group compared to the intervention group. According to guidelines has the patient to follow preparations and instructions to avoid tracer uptake in normal tissue and ensure a high quality.³ The present results may raise the question of the necessity of some of the patient preparations and adherence to instructions. However, this needs to be investigated further in larger populations with image quality as primary outcome measure.

Patient satisfaction, knowledge and discomfort

Patient satisfaction with care was high in study I and II and it may be noted that the patients in these two studies had various diagnosis, and underwent different PET/CT examinations which were carried out by different nursing staff. This result is consistent with previous studies regarding patient satisfaction in connection with other diagnostic examinations such as MRI, cardiac SPECT/CT, PET/CT and various examinations at nuclear medicine departments.^{26,28,29,31} The high patient satisfaction is also indicates a high quality of care in connection to the PET/CT examinations, since patient quality of care has a close relationship between patient satisfaction and the interaction between the patient and the staff that delivers care.²⁰⁻²² However, not all patients gave the response “to a very high degree” according to Collins *et al.* there is a difference in the degree of satisfaction if the patient not give the highest score means something is missing.²⁵ There is thus, still room for improvement of care. In the present studies were the lowest satisfaction scores obtained about the information the patients received prior the PET/CT examination. The findings also showed that the knowledge about the PET/CT examination was low, especially among the patients in study I. These results gave the idea to study IV that evaluates the effects of web-based information on patient satisfaction and image quality in connection to ¹⁸F-FDG PET/CT examination. The results of study I indicates that the information before PET/CT examinations needs to be improved. This is similar to Rosenkrantz *et al.* who found that patients undergoing examinations at a nuclear medicine department had the lowest knowledge about their examination compared to patients undergoing other diagnostic examinations.⁶⁶ The experienced discomfort during the PET/CT examination was low in study I,

II and IV with regard to exhaustion and claustrophobia and there were no difference regarding discomfort between those patients that had undergone the ^{18}F -fluoride PET/CT examination before and those who underwent it for the first time. The comments written by the patients in study I, II and IV on what they considered exhausting showed that it was the time spent in the PET/CT scanner and the fixed positioning of the body during that period that was considered the most strenuous by the patients, especially the arms position, elevated over the head. If the arms are positioned at the patients' side there is a significant risk for image artifacts.⁶⁷ In a study by Brechtel *et al.* a vacuum device was used for the positioning of the patient and supporting the arms elevated over the patients head during an ^{18}F -FDG PET/CT examination, thus improving patient comfort and image quality.⁶⁸ It is thereby suggested to try different interventions to improve patient comfort during the spent time in the PET/CT scanner.

Image quality

The image quality was evaluated as high in study II and only one patient's images had small artifacts. The result is similar to study IV where the image quality also considered as high regarding overall diagnostic accuracy. However, the image quality parameters that were assessed were different between study II and IV and are therefore not completely comparable. In study II, there was no difference in image quality between those patients that experienced pain or discomfort during the ^{18}F -fluoride PET/CT examination and those patients that did not experience pain or discomfort, or with regard to the patient's previous knowledge of the examination. One possible reason for these findings might be that most of the patients in the present study had none or only few bone metastases. A study by Czerw *et al.* found that prostate cancer patients with metastatic disease use coping strategies to control their pain.⁶⁹ This may partly explain our results. It also indicates that patients manage to go through the PET/CT examination and follow the instructions from the nursing staff even when they experience discomfort.

Health-related quality of life, perceived stress and physical activity

In study I the HRQoL, perceived stress and physical activity were low among the patients. However, the results of study II showed that the patients HRQoL was high and in study IV was the HRQoL relatively low and patients' levels of perceived stress slightly elevated. In study I there were some statistically significant correlations between patients' experiences of the ^{18}F -FDG PET/CT examination and HRQoL, perceived stress, physical activity

and knowledge, i.e. was worse fatigue correlated with low satisfaction and high discomfort. This is partly similar with findings in study IV that showed a correlation between worse fatigue and low patient satisfaction regarding the information about they would receive the results of the ^{18}F -FDG PET/CT examination. Fatigue was also the highest EORTC-QLQ-C30 single-item score in both study I and IV. Fatigue was the most common symptom with lung cancer patient and this group of patients also have unmet supportive care needs which much taken inconsideration by the clinical staff to improve overall care.⁷⁰ Patients with lung cancer are likely to experience fatigue and it has a more negative impact on the patients HRQoL than depression and anxiety.⁷¹ It is thereby suggested that the nursing staff that carry out the PET/CT examination try to identify these patients to improve patient satisfaction and overall care.

Patient experiences of ^{18}F -FDG PET/CT in a fixation mask

Interviews may provide a deeper understanding of patients experiences compared to questionnaires and study III was conducted using a phenomenological methodology according Max van Manen⁴⁶ which provides this knowledge by gaining into the lifeworld of the patient. In the present study patients' lifeworld changed during the ^{18}F -FDG PET/CT in a fixation mask examination. They could not control space or time and the lived body was restricted during the uptake phase, in the PET/CT scanner and fixation mask. They were now dependent on the nursing staff and different feelings such as helplessness, uncertainty and abandonment were heightened. They wanted support and reassurance from the nursing staff and to know that they not were forgotten. These findings are similar to patients' experiences of undergoing MRI.²⁸ Who described the patients' experiences as being in an unfamiliar situation that was a threat to the patients' self-control and they looked for support from the nursing staff. The greater the experienced threat and the need to handle the situation, the greater need for support from the nursing staff during examination procedure.²⁸ In the present study, lying in the fixation mask which squeezed and pressed on the patients face, the fixation mask was hopeless to get away from, and thereby affected the lived body and lived space. Patients found it hard to be able to communicate with the nursing staff when they was lying in the fixation mask but would have wanted to do so. This is similar to findings by^{72,73} that patients' perception of being covered with a fixation mask during radiotherapy was a distressing experience that negatively affected the patient's ability to communicate during that period. The staff that carried out the radiotherapy treatment played hereby an import role to make the patient safe and secure and able to go through with the radi-

otherapy treatment.^{72,73} In the present study some patients considered the ¹⁸F-FDG PET/CT examination in a fixation mask as tough while other patients did not. However, what all patients seemed to agree on was that the examination was something they had to pass through and the use of different coping strategies helped the patient during the examination procedure. It is thereby suggested to improve information before and during the ¹⁸F-FDG PET/CT examination in a fixation mask.

Methodological considerations

In study IV was the recruitment of patients completed before the intended number of patients were included, leading to an insufficient power regarding the primary outcome measure overall satisfaction. The reason was several encountered setbacks regarding the inclusion of patients such as an increasing workload with the nursing staff at the nuclear medicine department who assessed incoming PET/CT referrals for eligibility. It might thereby be assumed that some patients were missed which not is possible to control afterwards. There were also a higher number of patients that declined to participate than expected, and many patients were difficult to reach by phone or had their time for appointment to close in time after the notice for the ¹⁸F-FDG PET/CT examination was sent out. There were also a number of patients were not able to participate since the web-based information required access to internet. This all made the time of inclusion of the patients longer than anticipated. It is suggested to have an especially employed nurse that is responsible for the inclusion of patients, who if possible will ask the patient about participation at a personal meeting. It is also suggested to find ways to give patients access to internet if they not have that. Since this was the first study on this topic it provides valuable knowledge about the effects of web-based information on patient satisfaction in connection to an ¹⁸F-FDG PET/CT examination and image quality that may be used in future studies in larger populations.

In study I, II and IV were questionnaires used to collect information. Some of the questions were project-specific questions and thereby not tested for validity and reliability. This is limiting the internal validity of these studies. All studies had high response rates, no one was below 88% and all studies had a low number of unanswered questions which indicates that the questions were easy to understand and deemed as relevant for the patients which increases the reliability of the results. Some questions were from questionnaires that had previously been tested for validity and reliability. These questions had also high response rates. The questions with the lowest response rate were from EORTC-QLQ-PR25 used in study II and were about the use of incontinence aid and sexual function. They may thereby have been con-

sidered as to personal. However, since this not was the main aim of the study did it not have a major impact of the results.

In study I and II were the patients asked about participation of the author or the nursing staff that carried out the PET/CT examination directly after the PET/CT examination was conducted which may have affected the patient in the decision to agree to participate in the studies. It may be difficult for the patient to decline participation since they may feel that they are depended of the nursing staff to receive the results of the examination as soon as possible. They may also have agreed to participate because they felt that they had to as gratitude towards the nursing staff. However, the patients had the possibility to withdraw their participation at any time, no patient choose to do that. It is suggested that in future studies the person that is responsible for the inclusion of patients is independent at not belong to the group of nursing staff that take care of the patient to avoid bias. Being asked about participation by the nursing staff that carried out the PET/CT examination may also have influenced some patients to give false-positive responses to the questions regarding patient satisfaction and discomfort. However, since the results are clear and also similar to other studies regarding patient satisfaction is this deemed to have a minor impact of the results but must be taken into consideration

In study I, III and IV were only patients included that had not done a PET/CT examination before. This was to avoid that the patients previous experiences should influence the questions that were investigated. In study II were both patients that underwent the PET/CT examination for the first time and those patient that had undergone a PET/CT examination before included in the study. The main reason for this was that an ^{18}F -fluoride PET/CT examination at that period was a relatively uncommon examination. However, the analysis of comparing these two groups of patients regarding discomfort showed that there was no difference between these two groups of patients in this respect. This indicates that it not had a negative impact on the results of the study.

The inclusion criterion in the studies that all the patients had to be 18 years or older and Swedish speaking does that generalizability for the groups of patients that thereby are excluded not is possible.

Study I, II, and IV in this thesis have relatively small samples of participants which limits the external validity of the results and the generalizability to larger populations. However, since not many studies have been published about patients' perspectives of PET/CT examinations then these studies contribute with valuable knowledge on this topic.

Study III was a qualitative study using phenomenological methodology which requires smaller study populations than quantitative studies. Two to ten participants are recommended.⁷⁴ However, the results of a small sample size may be difficult to generalize to a larger population. The patients were asked about participation by the author after the ¹⁸F-FDG PET/CT in a fixation mask was carried out. More patients declined to participate (n=11) than those who agreed to participate. Possible reasons for this might be that they had fasted before the examination or that they did not manage due to their disease even though they had the possibility to attend an interview at a later date. Some patients were also missed due to administrative reasons. To increase the number of patients in future studies it is thereby suggested to have an especially employed nurse that have the possibility to ask all potential patients about participation in the study. It is also suggested to give the patient the possibility to eat, drink and rest before the interview if they so wish. The interviews in the present study were conducted by the author who work as a nurse at the department where the ¹⁸F-FDG PET/CT in a fixation mask was carried out and a conscious effort was made to avoid the pre-understanding of the investigated phenomena which is important when you use this research method to avoid influencing the results.⁴⁶ All the researchers within the project worked closely together throughout every step of the process which improved the trustworthiness and quality of the results.

Conclusions

Patient satisfaction with care was high with regard to both overall satisfaction and single variables in the intervention group and standard care group. There was no statistically difference between the intervention and standard care groups. However, there were some correlations between patient satisfaction and HRQoL. The image quality was high in both groups regarding overall diagnostic accuracy. However, there were a slightly higher number of detected image quality defects in the standard care group. The web-based information helped the patient to prepare before and to undergo the ^{18}F -FDG PET/CT examination. The effect of web-based information on patient satisfaction and image quality needs to be investigated in larger groups of patients and it is important to find ways to ensure a high inclusion of patients.

The majority of patients in the present studies were satisfied with care in connection to the PET/CT examination. However, the lowest satisfaction scores were regarding the information the patients received before the examination, the communication with the nursing staff that carried out the PET/CT examination and information about how they received information about the results of the PET/CT examination.

Many patients had little knowledge about what an ^{18}F -FDG PET/CT and an ^{18}F -fluoride PET/CT examination was and how it was conducted prior to the examination.

Most patients did not consider the PET/CT examination as exhausting or did experience claustrophobia during the procedure. However, the comments patients wrote on what they thought was exhausting during procedure show that it was the time spent in the PET/CT scanner and the fixed positioning of the body, especially the arms position that was experienced as the most exhausting.

Cancer patients that undergo an ^{18}F -FDG PET/CT examination may have a relatively low HRQoL and can experience symptoms such as fatigue. The nursing staff that carries out the PET/CT examination should have awareness that this may affect patients' experience of the examination.

The ^{18}F -fluoride PET/CT image quality was evaluated as high and there was no difference in image quality between those patients that experienced pain or discomfort during the examination procedure and those that did not experience pain or discomfort.

The ^{18}F -FDG PET/CT examination in a fixation mask was experienced as distressing and difficult of some patients but not of all. However, what all patients appeared to have in common was that the examination was something that had to be endured and the use of different coping strategies helped them to maintain composure during the examination procedure.

Clinical implications and future research

The results of this thesis may be used to improve patient information and care in connections to PET/CT examinations and thereby help optimize PET/CT examination procedure. However, the results need to be investigated further in larger populations.

It is suggested to try different interventions to improve patient information before and during the PET/CT examination, and patient comfort and communication between patient and nursing staff during the time the patient is in the PET/CT scanner.

The effects of web-based information on patient satisfaction and image quality in connection to PET/CT examinations needs to be investigated further in larger groups of patients using image quality as a primary outcome measure.

It is suggested to investigate patient experience and satisfaction with care in connection to PET/CT examinations in other groups of patients and PET/CT examinations with other tracers than ^{18}F -FDG and ^{18}F -fluoride.

Svensk sammanfattning (Swedish summary)

Syftet med denna avhandling var att undersöka patienters upplevelser av PET/CT undersökningar. Tillfredsställelsen med vården i samband med undersökningarna och om web-baserad information kan förbättra patient tillfredsställelsen och bildkvaliten jämfört med sedvanlig vård. Ett ytterligare syfte var att undersöka hur patient tillfredsställelsen med vården och bildkvaliten var korrelerad med den hälso-relaterade livskvaliten och upplevd stress.

Studie I

Hade som främsta syfte att undersöka patienters med känd eller misstänkt cancerdiagnos, kunskap om och upplevelse av en ^{18}F -FDG PET/CT undersökning. Genomfördes som en enkätstudie där 169 patienter som genomgick undersökningen för första gången deltog. Resultaten visade att få patienter kände till undersökningen. Majoriteten av patienter var nöjda med vården i samband med undersökningen. Det som de var minst nöjda med var informationen innan undersökningen. Få patienter upplevde obehag under undersökningen men de kommentarer som de skrev visade att det var tiden i PET/CT kameran och framförallt armarnas positionering som gav obehag.

Studie II

Hade som syfte att undersöka prostata cancer patienter med skelettmetastaser kunskap, tillfredsställelse och upplevelser av att genomgå en ^{18}F -fluoride PET/CT undersökning. Ett annat syfte var att undersöka om smärta eller obehag under undersökningen påverkade bildkvaliten negativt. Studien genomfördes som en enkätstudie och 46 patienter deltog. Resultaten gällande kunskap, tillfredsställelse och upplevelse av undersökningen var i stor utsträckning överensstämmande med resultaten från studie I. Utvärderingen av bildkvaliten visade att bildkvaliten var hög och att det inte var någon skillnad mellan de patienter som upplevde smärta eller obehag under undersökningen och de patienter som inte gjorde det.

Studie III

Denna studies syfte var att undersöka hur patienter med huvud- och hals cancer upplevde att genomgå en ^{18}F -FDG PET/CT undersökning i en fixations mask. Studien genomfördes som en intervjustudie med fenomenologisk ansats enligt Max van Manen. Nio patienter som inte hade genomgått under-

sökningen tidigare inkluderades i studien. Resultatet visade att patienternas upplevda livsvärld förändrades under undersökningen. Det som alla patienter hade gemensamt var beslutsamheten att genomgå undersökningen oavsett vilket obehag den än gav dem och att användandet av olika coping strategier hjälpte patienterna med detta.

Studie IV

Denna studie hade som syfte att undersöka effekterna av web-baserad patient information på patient tillfredsställelsen vid en ^{18}F -FDG PET/CT undersökning, kunskapen om undersökningen och bildkvaliten jämfört med sedvanlig vård. Studien var en randomiserad kontrollerad studie och 148 patienter som genomgick undersökningen för första gången randomiserades till antingen en kontrollgrupp som fick sedvanlig information om undersökningen eller en interventionsgrupp som dessutom fick tillgång till ett web-baserat informationsmaterial som förklarade hur undersökningen går till och varför patienten måste genomgå förberedelser och följa instruktioner från vårdpersonalen under undersökningens genomförande. Kunskapen och patienttillfredsställelsen mätes med hjälp av ett frågeformulär och bildkvaliten med ett bildkvalitets utvärderingsinstrument. Resultatet visade att det inte var några statistiskt signifikanta skillnader mellan interventionsgruppen och kontrollgruppen. Patienttillfredsställelsen var hög i båda grupperna. Det som patienterna var minst nöjda med var informationen om hur de skulle få reda resultatet av PET/CT undersökningen. Bildkvaliten var hög både i interventionsgruppen och i kontrollgruppen men förekomsten av bildkvalitetsdefekter var något högre i kontrollgruppen jämfört med interventionsgruppen. Den web-baserade informationen hjälpte patienterna att förbereda sig inför och att genomgå ^{18}F -FDG PET/CT undersökningen. Resultatet begränsas dock av bristen på power gällande det primära utfallsmåttet generell patient tillfredsställelse eftersom inkluderingen av patienter avslutades i förtid.

Slutsats

Resultaten av den här avhandlingen kan användas för att förbättra patient informationen och patientomhändertagandet i samband med PET/CT undersökningar och därmed hjälpa till att optimera undersökningarnas genomförande. Resultaten behöver dock undersökas vidare i större grupper av patienter.

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Appendices

FRÅGEFORMULÄR

Instruktion

Frågeformuläret består av olika delar:

Först en del med bakgrundsfrågor som beskriver vem du är och hur din hälsa är just nu. Sedan följer frågor där vi försöker få mera kunskap om dina förväntningar och upplevelser inför och under en PET-FDG undersökning. Den sista delen av frågeformuläret skall beskriva din hälsorelaterade livskvalitet.

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måndag – fredag kl. 08.00 – 12.00 samt 13.00 – 16.00

Kodnummer
Datum

A Bakgrundsdata

Dagens datum

1	Kön Man <input type="checkbox"/> Kvinna <input type="checkbox"/>
2	Ålder år Längdcm Vikt.....kg
3	Är du: Gift/sambo <input type="checkbox"/> Ensamstående <input type="checkbox"/> Änka/änkeman <input type="checkbox"/>
4	Vilken är den högsta utbildning du genomfört? <div style="text-align: center;">Gymnasium</div> <div style="text-align: center;">fackskola</div> Grundskola realskola Högskola/universitet 0-4 år Högskola/universitet > 4 år <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
5	Hur många år har du gått i skola?.....
6	Vilken är din huvudsakliga sysselsättning? Sätt bara 1 kryss! <div style="text-align: center;">Sjukskriven</div> <div style="text-align: center;">funktionshinder</div> Yrkesarbete rehabilitering Utbildning Hemarbete Arbetslös Annat <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
7	Om du har eller har haft arbete: Vad arbetade du med senast?..... Vilket anser du är ditt yrke, din yrkesidentitet?.....
8	Vilken är din genomsnittliga månadsinkomst? (före skatt) 0 – 4999 5000 – 9999 10 000 – 14 999 15 000 – 19 999 <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> 20 000 – 24 999 25 000 – 29 999 30 000 – 34 999 mer än 35 000 <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
9	Röker du? Nej aldrig Av och till Dagligen Har slutat Snusar <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>

10	Har du någon eller några av följande långvariga sjukdomar?					
		Ja	Nej		Ja	Nej
	Hjärt-kärlsjukdom	<input type="checkbox"/>	<input type="checkbox"/>	Njursjukdom	<input type="checkbox"/>	<input type="checkbox"/>
	Diabetes	<input type="checkbox"/>	<input type="checkbox"/>	Blodsjukdom	<input type="checkbox"/>	<input type="checkbox"/>
	Cancersjukdom	<input type="checkbox"/>	<input type="checkbox"/>	Psykiska besvär	<input type="checkbox"/>	<input type="checkbox"/>
	Reumatisk sjukdom	<input type="checkbox"/>	<input type="checkbox"/>	Neurologisk sjukdom	<input type="checkbox"/>	<input type="checkbox"/>
	Astma eller allergi	<input type="checkbox"/>	<input type="checkbox"/>	Sköldkörtelsjukdom eller annan ämnesom- sättningsrubbnig	<input type="checkbox"/>	<input type="checkbox"/>
	Mag-tarmsjukdom	<input type="checkbox"/>	<input type="checkbox"/>			
Annan långvarig sjukdom						
11	Har någon av dina närmaste släktingar någon allvarlig sjukdom (eller har haft) Mor:..... Far:..... System/systrar:..... Bror/bröder:.....					
12	Följande frågor skall ge en bild av din stressnivå.					
		Nästan aldrig	Sällan	Ibland	Ofta	Nästan alltid
13	Känner du dig tidspressad	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14	Känner du dig pressad	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15	Känner du dig uppvarvad	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Ange din fysiska aktivitet under de senaste 12 månaderna. Nivån kan variera över året och under veckan, men försök ange ett genomsnitt.
16	<p>Daglig sysselsättning och/eller arbete</p> <p>Mest stillasittande <input type="checkbox"/></p> <p>Sitter ca hälften av tiden <input type="checkbox"/></p> <p>Mest stående <input type="checkbox"/></p> <p>Går mest, lyfter, bär lite <input type="checkbox"/></p> <p>Går mest, lyfter, bär mycket <input type="checkbox"/></p> <p>Tungt kroppsarbete <input type="checkbox"/></p>
17	<p>Promenad eller cykling</p> <p>Nästan aldrig <input type="checkbox"/></p> <p>Mindre än 20 minuter per dag <input type="checkbox"/></p> <p>20-40 minuter per dag <input type="checkbox"/></p> <p>40-60 minuter per dag <input type="checkbox"/></p> <p>1-1,5 timmar per dag <input type="checkbox"/></p> <p>Mer än 2 timmar per dag <input type="checkbox"/></p>
18	<p>Motion förutom det du angivit under promenad eller cykling.</p> <p>Nästan aldrig <input type="checkbox"/></p> <p>Mindre än 1 timme per vecka <input type="checkbox"/></p> <p>1-2 timmar per vecka <input type="checkbox"/></p> <p>2-3 timmar per vecka <input type="checkbox"/></p> <p>3-4 timmar per vecka <input type="checkbox"/></p> <p>4-5 timmar per vecka <input type="checkbox"/></p> <p>Mer än 5 timmar per vecka <input type="checkbox"/></p>

B Dessa frågor rör den undersökning, som kallas PET-FDG och som du nyligen genomgått.

- | | | | | | |
|----|--|---------------------------------------|---|--|---|
| 19 | Hur kallades du till undersökningen? | Per brev
<input type="checkbox"/> | Per telefon
<input type="checkbox"/> | Annat sätt
<input type="checkbox"/> | |
| 20 | Kände du till <u>före</u> undersökningen vad en PET-FDG undersökning är? | Inte alls
<input type="checkbox"/> | Något lite
<input type="checkbox"/> | En hel del
<input type="checkbox"/> | Jag kan mycket
<input type="checkbox"/> |
| 21 | Kände du till <u>före</u> undersökningen hur en PET-FDG undersökning går till? | Inte alls
<input type="checkbox"/> | Något lite
<input type="checkbox"/> | En hel del
<input type="checkbox"/> | Jag visste precis
<input type="checkbox"/> |

-
- | | | Inte alls | I liten grad | I någon grad | I hög grad | I mycket hög grad |
|----|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 22 | Är du nöjd med informationen du fick <u>före</u> undersökningen? | <input type="checkbox"/> |
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| 29 | Fick du intryck av att arbetet på sjukhuset var bra organiserat? | <input type="checkbox"/> |

30 Hur ansträngande tyckte du att undersökningen var?

Inte alls
ansträngande

Något
ansträngande

Ganska
ansträngande

Mycket
ansträngande

31 Om du tyckte det var ansträngande, vad var det som du upplevde som ansträngande?

32 Var undersökningen som du hade föreställt dig att den var?

Mycket lättare

Något lättare

Precis som jag
föreställt mig

Något värre

Mycket värre

Kände du dig instängd under undersökningen?

33

Inte alls

Något lite

Ganska mycket

Mycket instängd

Förslag till förändring: _____

om du vill skriva mera kan du använda baksidan

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Mycket
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Mycket lättare

Något lättare

Precis som jag
föreställt mig

Något värre

Mycket värre

Kände du dig instängd under undersökningen?

33

Inte alls

Något lite

Ganska mycket

Mycket instängd

Förslag till förändring: _____

om du vill skriva mera kan du använda baksidan

Quality assessment [18F]fluoride-PET/CT

A. Image artefacts

1. No artefacts
2. Minor artefacts
3. Major artefacts

B. Lesion conspicuity

1. Excellent lesion conspicuity
2. Intermediate lesion conspicuity
3. Poor lesion conspicuity

C. Extent of image impairment

1. All anatomical regions fully diagnostic
2. Diagnostic accuracy impaired in occasional anatomical regions
3. Diagnostic accuracy impaired in several anatomical regions

D. Overall diagnostic accuracy

1. Fully diagnostic examination
2. Minor impairment of diagnostic accuracy
3. Major impairment of diagnostic accuracy

E. Image findings

1. No bone metastases
2. Occasional bone metastases (1-5?)
3. Many bone metastases (>6?)

Comments.....

.....

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Kodnummer
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2	<p>Vilken är den högsta utbildning du genomfört?</p> <p style="text-align: center;">Gymnasium fackskola</p> <p>Grundskola <input type="checkbox"/> realskola <input type="checkbox"/> Högskola/universitet 0-4 år <input type="checkbox"/> Högskola/universitet > 4 år <input type="checkbox"/></p>								
3	<p>Hur många år har du gått i skola?.....</p>								
4	<p>Vilken är din huvudsakliga sysselsättning? Sätt bara 1 kryss!</p> <p style="text-align: center;">Sjukskriven funktionshinder</p> <p>Yrkesarbete <input type="checkbox"/> rehabilitering <input type="checkbox"/> Utbildning <input type="checkbox"/> Hemarbete <input type="checkbox"/> Arbetslös <input type="checkbox"/> Annat <input type="checkbox"/></p>								
5	<p>Om du har eller har haft arbete:</p> <p>Vad arbetade du med senast?.....</p> <p>Vilket anser du är ditt yrke, din yrkesidentitet?.....</p>								
6	<p>Röker du?</p> <p>Nej aldrig <input type="checkbox"/> Av och till <input type="checkbox"/> Dagligen <input type="checkbox"/> Har slutat <input type="checkbox"/></p>								
7	<p>Snusar du?</p> <p>Nej aldrig <input type="checkbox"/> Av och till <input type="checkbox"/> Dagligen <input type="checkbox"/> Har slutat <input type="checkbox"/></p>								
8	<p>Vilken är din genomsnittliga månadsinkomst det senaste året? (före skatt)</p> <table style="width: 100%; border: none;"> <tr> <td style="border: none;"><input type="checkbox"/> 0 – 4999 kr</td> <td style="border: none;"><input type="checkbox"/> 20 000 – 24 999 kr</td> </tr> <tr> <td style="border: none;"><input type="checkbox"/> 5000 – 9999 kr</td> <td style="border: none;"><input type="checkbox"/> 25 000 - 29 999 kr</td> </tr> <tr> <td style="border: none;"><input type="checkbox"/> 10 000- 14 999 kr</td> <td style="border: none;"><input type="checkbox"/> 30 0000 – 34 999 kr</td> </tr> <tr> <td style="border: none;"><input type="checkbox"/> 15 000 – 19 999 kr</td> <td style="border: none;"><input type="checkbox"/> Mer än 35 000 kr</td> </tr> </table>	<input type="checkbox"/> 0 – 4999 kr	<input type="checkbox"/> 20 000 – 24 999 kr	<input type="checkbox"/> 5000 – 9999 kr	<input type="checkbox"/> 25 000 - 29 999 kr	<input type="checkbox"/> 10 000- 14 999 kr	<input type="checkbox"/> 30 0000 – 34 999 kr	<input type="checkbox"/> 15 000 – 19 999 kr	<input type="checkbox"/> Mer än 35 000 kr
<input type="checkbox"/> 0 – 4999 kr	<input type="checkbox"/> 20 000 – 24 999 kr								
<input type="checkbox"/> 5000 – 9999 kr	<input type="checkbox"/> 25 000 - 29 999 kr								
<input type="checkbox"/> 10 000- 14 999 kr	<input type="checkbox"/> 30 0000 – 34 999 kr								
<input type="checkbox"/> 15 000 – 19 999 kr	<input type="checkbox"/> Mer än 35 000 kr								

B Dessa frågor rör den undersökning, som kallas PET-FDG och som du nyligen genomgått.

9	Kände du till <u>före</u> undersökningen vad en PET-FDG undersökning är?	Inte alls <input type="checkbox"/>	Något lite <input type="checkbox"/>	En hel del <input type="checkbox"/>	Jag visste mycket <input type="checkbox"/>	
10	Kände du till <u>före</u> undersökningen hur en PET-FDG undersökning går till?	Inte alls <input type="checkbox"/>	Något lite <input type="checkbox"/>	En hel del <input type="checkbox"/>	Jag visste precis <input type="checkbox"/>	
		Inte alls	I liten grad	I någon grad	I hög grad	
11	Är du nöjd med informationen du fick <u>före</u> undersökningen?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
12	Är du nöjd med informationen du fick <u>när du kom</u> till undersökningen?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
13	Har du sökt information om undersökningen någon annanstans?	Ja <input type="checkbox"/>	Nej <input type="checkbox"/>			
14	Om du svarat ja på förra frågan, var hittade du information?	<hr/>				
		Inte alls	I liten grad	I någon grad	I hög grad	
15	Är du nöjd med bemötandet du fick under besöket på nuklearmedicin?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
16	Pratade vårdpersonalen med dig så att du förstod vad de sa?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
17	Kände du att vårdpersonalen visade omsorg om dig?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
18	Hade du förtroende för vårdpersonalens yrkeskunskap?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
19	Tycker du att vårdpersonalen hade tillräckligt med tid när du behövde dem?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

-
- 20 Är du nöjd med informationen om hur du får besked om undersökningens resultat?
- 21 Fick du intryck av att arbetet på sjukhuset var bra organiserat?

22 Hur ansträngande tyckte du att undersökningen var?

Inte alls
ansträngande

Något
ansträngande

Ganska
ansträngande

Mycket
ansträngande

23 Om du tyckte det var ansträngande, vad var det som du upplevde som ansträngande?

24 Var undersökningen som du hade föreställt dig att den var?

Mycket lättare

Något lättare

Precis som jag
föreställt mig

Något värre

Mycket värre

25 Kände du dig instängd under undersökningen?

Inte alls

Något lite

Ganska mycket

Mycket instängd

Kan du med några ord beskriva vad som varit **mest påfrestande** för dig under besöket i samband med undersökningen:

Kan du med några ord beskriva vad som varit **mest positivt** för dig under besöket i samband med undersökningen:

Övriga kommentarer:

Frågor om utbildningen i internetportalen

1. Hur tycker du att det gick att hitta i internetportalen och att använda dess funktioner?

- Mycket lätt
- Ganska lätt
- Ganska svårt
- Mycket svårt

2. Presenterades innehållet så att det var lätt att förstå?

- Inte alls
- I liten grad
- I någon grad
- I hög grad
- I mycket hög grad

3. Upplevde du tekniska problem med internetportalen (t.ex. svårigheter att logga in, se bildspelet eller att läsa Vanliga frågor)?

- Inte alls
- Lite
- En del
- Ganska mycket
- Våldigt mycket

4. Vad tyckte du om tidpunkten då du fick tillgång till utbildningen i internetportalen?

- För tidigt, den borde presenteras vid en tidpunkt närmare undersökningen
- Det passade rätt i tiden
- För sent, jag hade velat ha tillgång till utbildningen tidigare

5. Hur stor nytta hade du av bildspelet?

- Ingen nytta alls
- Lite nytta
- Ganska mycket nytta
- Mycket nytta

6. Hur stor nytta hade du av den skrivna texten?

- Ingen nytta alls
- Lite nytta
- Ganska mycket nytta
- Mycket nytta

7. Hur stor nytta hade du av funktionen Vanliga frågor?

- Ingen nytta alls
- Lite nytta
- Ganska mycket nytta
- Mycket nytta

8. Hur stor nytta hade du av utbildningen i internetportalen i följande avseenden?

	Ingen nytta alls	Lite nytta	Ganska mycket nytta	Mycket nytta
Minskad oro i samband med undersökningen	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
Jag kände inge oro <input type="checkbox"/>				
Genomförandet av förberedelserna inför undersökningen	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
Kommunikationen med vårdpersonalen	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
Att genomgå själva undersökningen	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
Förståelsen för anvisningarna om vad som gäller efter undersökningen	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
Informationen om hur jag får reda på undersökningens resultat	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>

10. På det stora hela, hur nöjd är du med utbildningen i internetportalen?

- Väldigt nöjd
- Mestadels nöjd
- Varken nöjd eller missnöjd
- Ganska missnöjd
- Mycket missnöjd

11. Skulle du rekommendera utbildningen i internetportalen till någon annan som ska gå igenom samma PET/DT som dig?

- Ja, absolut
- Ja, det tror jag
- Nej, det tror jag inte
- Nej, absolut inte

Personnummer
Namn
Kodnummer

Formulär utvärdering bildkvalitet

1. Upptag stämband
 - a. Inget
 - b. Lite
 - c. Mycket
2. Muskel upptag
 - a. Inget
 - b. Lite
 - c. Mycket
3. Brunt fett
 - a. Inget
 - b. Lite
 - c. Mycket
4. Rörelse artefakter
 - a. Inget
 - b. Lite
 - c. Mycket
5. Aktivitet urinblåsa
 - a. Normalt fysiologiskt upptag
 - b. Onormalt fysiologiskt upptag
6. Övergripande diagnostisk bildkvalitet
 - a. God kvalitet
 - b. Intermediär kvalitet
 - c. Dålig kvalitet
7. Variant av upptag
 - a. Benign
 - b. Malign

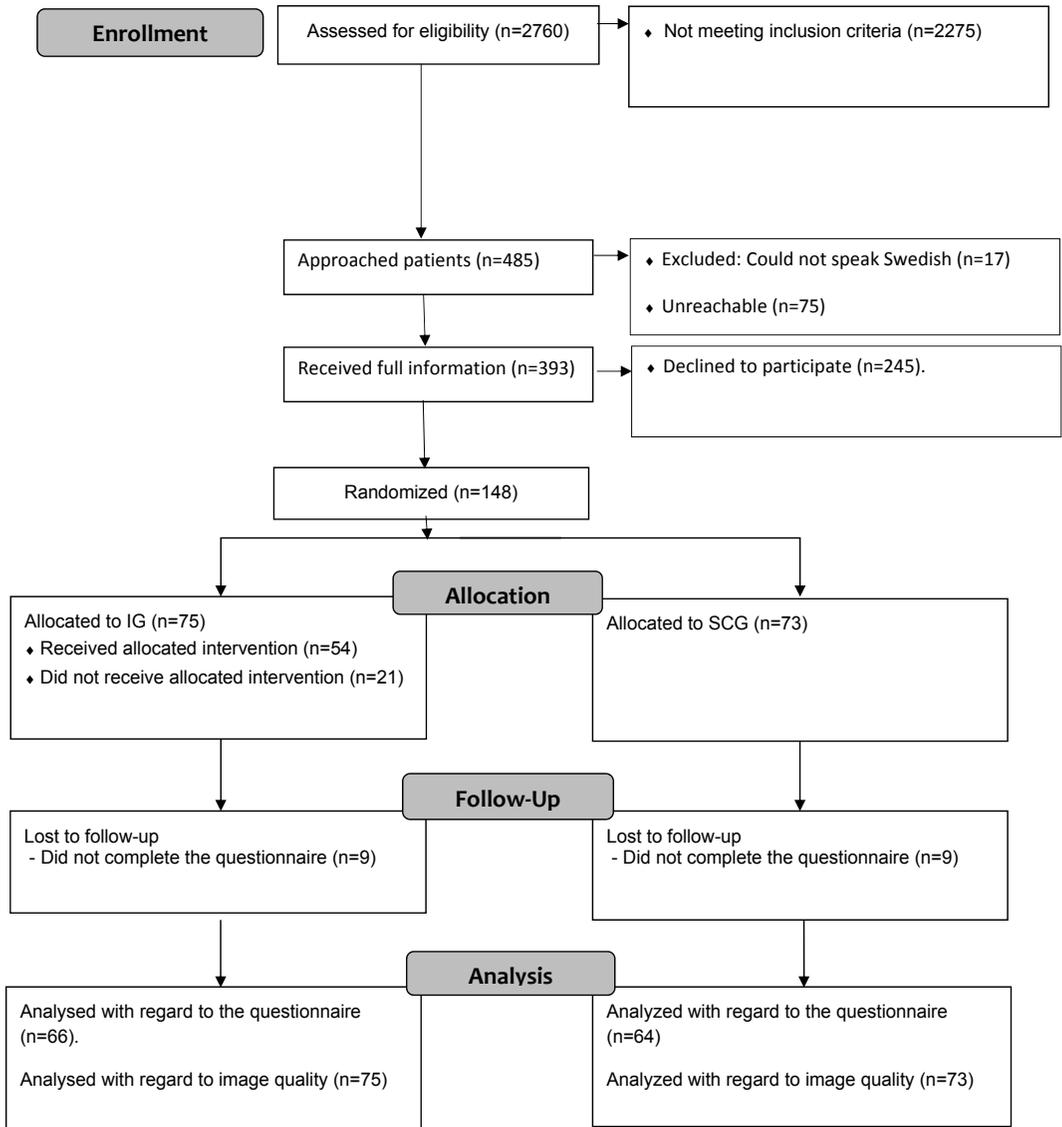


Figure 1. Participant flow

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