

FÆLLES ANSØGNINGSSKEMA TIL KVALITETS- OG UDVIKLINGSMIDLERNE UNDER KEU

--

REGION:	DATO:	LØBENR.: (udfyldes af regionen)
---------	-------	---------------------------------

STAMOPLYSNINGER

ANSØGERS NAVN, MAIL, TLF mm. Marie Germund Nielsen, Forskningsenheden for Almen Praksis, Institut for Folkesundhed, Aarhus Universitet. Bartholins Allé 2. 8000 Aarhus C. mm@ph.au.dk, tlf. nr. 42 26 18 80. PROJEKTANSVARLIG: ØVRIGE DELTAGERE (samarbejdspartnere eller tilknytning til forskningsinst. el.lign): Marie Germund Nielsen vil blive støttet af en Center for Forskning i Cancerdiagnostik i Praksis (CaP) -forskergruppe; Lektor, Anette Fischer Pedersen (støtte til ekspertise inden for psykologiske aspekter af undersøgelsen), Professor Peter Vedsted (støtte til forskellige aspekter af undersøgelsen), postdoc Line Flytkjær Virgilsen (ekspertise inden for epidemiologi og spørgeskemaundersøgelser), postdoc Henry Jensen (ekspertise i spørgeskemaundersøgelse og nationale registre), professor og praktiserende læge Frede Olesen (ekspertise inden for sundhedssystemet generelt) og statistiker Alina Zalounina Falborg.

PROJEKTBESKRIVELSE

PROJEKTETS TITEL: Cancerrecidiv i almen praksis: patienternes oplevelse og den praktiserende læges rolle. PROJEKTETS (ANSØGNINGENS) EMNE: Forskning i cancer recidiv i Almen praksis. OPDATERING VEDR. TIDLIGERE AFHOLDT PROJEKT (sæt x): NYOPRETTET PROJEKT (sæt x): ☒ FORMÅL: Målgruppe Vi planlægger at udsende spørgeskemaer til 3000 praktiserende læger i hele Danmark, og håber på at 2250 læger (75%) besvarer spørgeskemaet. Af de 375 ydernumre der er i Region Midtjylland, forventer vi at 281 besvare spørgeskemaet. Mål og forventet resultat Formålet med undersøgelsen er at belyse forløbet fra første symptom til behandlingsstart for tilbagefald (recidiv) efter kræft hos patienter i Danmark. Dette gøres ved at undersøge varigheden af tidsperioder mellem vigtige milepæle såsom første besøg hos egen læge, første henvisning o. lign. samt hvilke undersøgelser lægen igangsatte, hvordan lægen henviste, og om der var utilsigtede hændelser i forløbet. Undersøgelsens specifikke formål er; 1) Beskrivelse af diagnostiske forløb blandt patienter med recidiv af kræft, herunder om diagnosen er baseret på symptompræsentation eller rutinemæssig opfølgning.
--

2) Beskrivelse af de kliniske præsentationer hos symptomatiske patienter diagnosticeret med recidiv. 3) Undersøgelse af de specifikke tidsintervaller i det diagnostiske forløb for patienter med recidiv af kræft (dvs. patient, GP, systemintervaller). 4) Undersøge sammenhængen mellem psykosociale karakteristika hos patienter diagnosticeret med recidiv (fx frygt for tilbagefald, fatalistisk syn på kræft, socioøkonomisk status) og deres lægesøgningsadfærd. 5) Undersøgelse af, om lægerne føler sig trygge i forhold til opfølgning af kræftpatienter efter behandling, og hvordan de oplever det faglige forhold med hospitalslægerne. 6) Undersøgelser af, hvad der udløser mistanke om recidiv blandt praktiserende læger i opfølgningen af kræftpatienter.
PROJEKTBESKRIVELSE (kort resumé) – (Se desuden vedlagte projektbeskrivelse bilag 1.) Omkring 35.000 danskere diagnosticeres hvert år med kræft og heldigvis stiger overlevelsen. Sygehusenes standardiserede opfølgningsprogrammer er under udvikling bl.a. som følge af det øgede pres fra det stigende antal patienter og manglende evidens for effekt. Fremover kommer en del af rutinekontrollerne til at foregå hos den alment praktiserende læge. Imidlertid mangler vi viden om forløbet op til diagnosen af sygdomstilbagefald, herunder den alment praktiserende læges rolle. Dette er afgørende at få belyst, hvis vi skal skabe tryghed for patienterne og sikre, at de praktiserende læger er klædt på til at opdage tilbagefald af kræft i tide. Dette projekt vil undersøge lægesøgningsadfærd i tiden op til en diagnose af tilbagefald af kræft, patienternes symptomer og lægens tolkning og handling på symptomerne samt hvem der er involveret i udredningen. Patienter med tilbagefald af kræft identificeres gennem danske nationale registre. Der udvikles to spørgeskemaer. Det første spørgeskema sendes til patienter med nyligt konstateret tilbagefald. Det skal give indsigt i patienternes lægesøgningsadfærd, frygt for tilbagefald, psykosociale karakteristika samt oplevede symptomer i perioden før diagnosen af tilbagefald. Det andet spørgeskema sendes til patientens praktiserende læge og skal bl.a. belyse lægernes vurdering og tolkning af patientens præsenterede symptomer i perioden op til diagnosen samt deres vurdering af egne kompetencer til at håndtere problemstillingerne for den enkelte kræftpatient og eventuelle uækkede behov for sparring med onkologiske kolleger. Den nye viden kan blive brugt direkte som led i planlægning og implementering af opfølgningsprogrammer i almen praksis. Endvidere vil projektets resultater kunne anvendes til at identificere specielle fokusområder for den praktiserende læge og for sundhedsplanlæggere med det formål at diagnosticere tilbagefald af kræft tidligere og derved forbedre patientens prognose. Samtidig skal resultaterne bidrage til at sikre effektive opfølgningsprogrammer, der giver patienten tryghed og kompetent støtte og monitorering.
EVALUERING (metode og tidsramme samt plan for implementering og formidling) 1) I dette projekt laver vi pilottest og evaluerer metoder og performance af algoritmerne til at identificere patienterne med kræft for anden gang i registrene, og herefter laver eventuelle justeringer. 2) Under udviklingen af spørgeskemaet har vi gennemført en pilottest af spørgeskemaet blandt patienter på onkologisk afdeling.

Projektet forventes at resultere i følgende publikationer; 1) Routes to diagnosis of patients with cancer recurrence. 2) Symptom presentation in general practice among patients with cancer recurrence. 3) Time intervals from first symptom to diagnosis among patients with cancer recurrence. 4) GP suspicion of cancer recurrence in the aftercare for cancer survivors. 5) Diagnostics and follow-up of cancer survivors: the GP's perspective. 6) Associations between psychosocial characteristics and help-seeking behaviour in patients with cancer recurrence. <u>Tidsramme:</u> Pilottestningen af algoritmerne foregår i maj-juni 2018. Selve dataindsamlingen løber fra september 2018 og 1½ år frem.
<i>Vurdering/overvejelse om efterfølgende udbredelse og implementering i almen praksis</i> Gennemførelsen af dette projekt vil give ny viden, der kan bruges direkte som led i planlægning og implementering af opfølgningsprogrammer for kræft i almen praksis. Opfølgningsprogrammer for kræft blev iværksat i 2015 og er stadig under udvikling og implementering. Resultaterne skal også bruges til at identificere specielle fokusområder for de praktiserende læger og sundhedsplanlæggere, så tilbagefald af kræft kan diagnosticeres optimalt og derved forbedre patienternes oplevelse og prognose. Resultaterne vil dermed også være med til at sikre effektiv opfølgning, der giver patienterne tryghed, kompetent støtte og tæt monitorering. Projektets resultater har stor samfundsmæssig relevans, da diagnostikken af kræft-tilbagefald endnu ikke er belyst med udgangspunkt i almen praksis, og dermed har man heller ingen viden om patienternes perspektiv herpå. Denne viden er essentiel for at kunne videreudvikle og støtte de praktiserende læger i diagnostikken af både tilbagefald og nye kræfttilfælde. START- OG SLUTTIDSPUNKT (evt. forventet): 01-07-2017 til 01-02-2020

BUDGET
ANSØGT BELØB (2): 74.475 kr.
BEVILLING (indeværende år og evt. efterfølgende år):
ANSØGT MIDLER SPONSERET FRA ANDRE SIDER:
BUDGET FORDELT PÅ ÅR:
TOTALBUDGET: 3.373.980 kr.

AFSLUTTENDE RAPPORT/ARTIKEL SENDES TIL DET REGIONALE SEKRETARIAT:
SUPPLERENDE OPLYSNINGER:
BILAGSFORTEGNELSE:
Bilag 1. Projektbeskrivelse.
Bilag 2. Detaljeret budget.

- (1) I forbindelse med evaluering skal projektet forholde sig til mulighederne for at anvende Triple Aim .
- (2) Et udspecificeret budget vedlægges, hvor det er markeret præcist, hvilke midler der ansøges om hos KEU.

Cancer recurrence:

Patient experience and the role of general practice

Applicant: Postdoctoral fellow Marie Germund Nielsen, MScPH

Project group: Associate professor Anette Fischer Pedersen, PhD, MSc in Psychology
Postdoctoral fellow Line Flytkjær Virgilsen, PhD, MScPH
Postdoctoral fellow Henry Jensen, PhD, MHS
Professor Peter Vedsted, MD

Institution: Research Centre for Cancer Diagnosis in Primary Care (CaP), Aarhus University
Research Unit for General Practice & Section for General Medical Practice,
Department of Public Health, Aarhus University, Bartholins Allé 2, 8000,
Aarhus C, Denmark

Summary

The proportion of cancer survivors is increasing, and 5% of the Danish population live with a cancer diagnosis (1). The aftermath of a cancer diagnosis is associated with increased need for physical and psychological aftercare caused by late effects of treatment and fear about recurrence or new cancer (2,3). The prognosis for this group depends on the ability of the healthcare system to respond adequately to early signs of cancer recurrence. General practice is intended to play a significant role in the future Danish cancer follow-up programme, but little is known about the diagnostic route to cancer recurrence.

Aims

The overall aim of this project is to study the route to diagnosis of recurrent cancer by focusing on the patients' experiences during the time before the diagnosis of recurring cancer and the role of general practice. The specific aims will be:

- 1) To describe the route to diagnosis among patients with recurrent cancer, including whether the diagnosis is based on symptom representation or routine follow-up.
- 2) To describe the patients' perceptions and clinical presentation of symptoms of recurrent cancer.
- 3) To study the time intervals in the diagnostic pathways for patients with cancer recurrence (i.e. patient, general practitioner (GP), diagnostic interval and system intervals).
- 4) To study the association between psychosocial characteristics of patients diagnosed with cancer recurrence (e.g. fear of recurrence, cancer fatalism, socio-economic position) and their help-seeking behaviour.
- 5) To study GPs' confidence concerning own ability to provide care for cancer patients in remission and the GPs' view on the collaboration with hospital-based oncology consultants.
- 6) To explore clinical triggers for GPs' suspicion of recurrence in former cancer patients.

Perspectives

This project will provide new knowledge on the patients' perceptions and presentation of symptoms before a diagnosis of cancer recurrence. As for our previous research on primary cancer diagnosis, this study will provide basic knowledge on routes and time intervals, which can change the paradigm for follow-up.

The project will provide important new knowledge on the diagnostic route to cancer recurrence in general practice, whereby health care planners can optimise follow-up programmes (7). This information can be used to develop effective and efficient follow-up programmes for cancer (4), ensure better integration of general practice in the follow-up (6) and ultimately lead to better prognosis and quality of life for the patients.

Internationally, this project will provide important new findings in a field that has only been sparsely researched. As more and more patients will become cancer survivors in the future, more and more patients will also experience recurrence. Therefore, knowledge about the diagnosis of recurrence is urgent.

The results from this project may thus serve as a step towards earlier diagnosis of cancer recurrence, better prognosis for the patient and higher patient satisfaction.

Background

The American Cancer Society defines cancer recurrence as *“the return of cancer after treatment and after a period of time during which the cancer cannot be detected. The same cancer may come back where it first started or somewhere else in the body”* (8). The risk of cancer recurrence varies considerably as it is influenced by factors such as age, cancer type and cancer stage at the diagnosis of the initial cancer. Reported recurrence rates are 2-40% among colorectal cancer patients (9-11), 23% among stages I–III for lung, breast and prostate cancer patients (12), and 90% among ovarian cancer patients (13). Patients in cancer remission have a higher risk of subsequent primary cancer; a relative risk of 17% for women and 11% for men has been reported (14). Early diagnosis of recurrence can improve the prognosis and increase the survival in patients with cancer (15).

Cancer-free patients are usually offered a routine follow-up programme, which traditionally has been managed in a hospital setting in the secondary healthcare sector. Some of the existing follow-up programmes have shown not to be sufficiently effective in reducing cancer mortality (16,17). Consequently, the Danish follow-up programmes are currently under revision (18), and general practice in the primary healthcare sector is intended to play a greater role than today (19). This calls for increased collaboration between sectors and better integration of oncological knowledge in general practice (20). A recent study by Easley et al. reported that general practitioners (GPs) were challenged by communication problems and lack of clearly defined roles for the various healthcare providers involved in the treatment of cancer patients, whereas medical specialists expressed concerns about limited access to GP care for the patients (21).

Only one paper published in the UK in 1996 has examined the consequences of transferring the primary responsibility for follow-up of breast cancer from the hospital to general practice for patients in remission. This study found no significant difference in the time to the diagnosis of cancer recurrence between women who received routine care and women who received follow-up care provided by the GP (22). The route to diagnosis of recurrence is not well described in the literature. However, a recent study indicated that almost half of all patients with recurrent cancer are diagnosed outside the regular follow-up scheme (23). To offer better follow-up programmes, we need more knowledge about the route to diagnosis of recurrent cancer in Denmark. We specifically need to know whether the diagnosis is primarily based on symptom presentation or whether cancer recurrence is detected through the standard follow-up programmes. Additionally, we need to know how and when patients diagnosed with symptomatic cancer recurrence seek medical help through their GP.

The proportion of patients experiencing symptoms before their recurrence diagnosis varies with cancer type and disease stage. One study found that only 28% of patients with ovarian cancer recurrence had symptoms at the time of diagnosis (24), whereas a report estimated that 41-91% of patients with cervical cancer recurrence had experienced symptoms (25). Many cancer survivors have chronic late effects and comorbidity (26). These patients may have difficulty differentiating between long-term side effects of cancer treatment and possible signs of recurrence. Patients may also falsely “feel safe” because they attend the regular controls. Furthermore, we know that post-traumatic stress symptoms are common among cancer survivors (26). In combination with their previous experiences, this may also influence their help-seeking behaviour when they experience symptoms (17,27). Also a recent study by Ellegaard et al. found that breast cancer survivors experience substantial unmet needs years after end of treatment (5). The new follow-up programmes will have increased focus on the individual patient, as the individual patient according to recommendations should feel safe in the chosen follow-up (18).

The literature is also limited on GP reactions to the presentation of symptoms by cancer survivors. We have no knowledge about what triggers the suspicion of recurrence among GPs, and it has not been established whether the GPs generally feel qualified to be involved in cancer follow-up programmes. A Norwegian study found that the GPs acknowledged the importance of providing follow-up care to cancer patients and that the majority of GPs felt confident in own ability to provide such care (28). Meanwhile, GPs in other studies have identified needs for improved guidelines, more collaboration and further education before being willing to have responsibility for the follow-up care of adult cancer survivors (21,29). In a recent national cancer patient survey, 15% of the cancer patients reports that their own GP lacks knowledge about their cancer disease. Only 8% want the follow-up program to be performed by a GP while 85% want the doctor in a hospital (30). Knowledge in this area may provide valuable insight into the diagnostic pathway of cancer recurrence to ensure early diagnosis and better support for the patients and offer the best and most efficient individual health care. The limited research in this field is a major barrier for establishing evidence-based clinical guidelines and is also accompanied by limited awareness among health care professionals as to the psychosocial and clinical needs of survivors (31).

Scientific method

Research setting

The Research Centre for Cancer Diagnosis in Primary Care (CaP) at Aarhus University conducts research within the diagnostic pathway for cancer, specifically on primary cancer diagnosis (32-36). CaP started a dedicated research series in 2015 focusing on the route to diagnosis of cancer recurrence. One of the aims in an ongoing PhD project is to develop algorithms to identify recurrent cancers in Danish registries. The algorithms are under validation with promising results and will provide a stepping stone for this project.

Design and population

This study will be carried out as a retrospective cohort study. Using the above-mentioned algorithm, we will identify a population of patients with recurrent cancers diagnosed between 1 January 2018 and 31 December 2018 defined as the CaP recurrence cohort and their GPs. Lung, breast, colorectal, malignant melanoma, bladder, ovary/endometrial, and head and neck cancer will be included. Combined analyses of all seven cancer types are also planned. Data on retrospective exposures in this cohort will then be collected.

Data sources

The project will include data from Danish national registries combined with questionnaire data.

Identification of recurrence cancer patients

An algorithm for colorectal cancer recurrence developed by Timothy Lash et al. has shown a sensitivity of 95% and a specificity of 97% (9). This algorithm is currently being validated in another Danish study. The development and validation of an algorithm for bladder cancer has just been finalised. The development and validation of an algorithm for breast cancer is currently ongoing. Algorithms for lung, malignant melanoma, ovary/endometrial, and head and neck cancers are all planned to be completed in 2017. Permissions and co-operation agreements are in progress for all of these cancer types.

Danish national registries

The Danish National Patient Register and the Danish National Pathology Register will be used to identify cancer recurrence based on the above mentioned PhD work. Statistics Denmark will provide sociodemographic data on the patients.

CaP recurrence cohort

Two surveys are planned in this project to study the diagnostic process for cancer recurrence: The first survey will be aimed at patients diagnosed with cancer recurrence, and the second will be aimed at their GP. We plan to collect data for one year (2018) to ensure a sufficiently large population of patients with cancer recurrence ($N \approx 5000$). After identification of patients with cancer recurrence through Danish national registries, patients who are still alive will receive a questionnaire. All GPs of included patients will also receive a questionnaire after consent from the patients. The data collection and the planned studies will be developed on the basis of the experience and expertise gained from the previous studies conducted by CaP in this field (32).

Power calculation

We expect to include 3,000 patients with newly diagnosed cancer recurrence during the data collection period and data collection will proceed until this number is reached. The estimate is based on the prevalence of recurrence of various cancer types available from previous studies. A sample of 3,000 will give a satisfactory statistical precision for describing the outcomes in the descriptive analyses (aims 1-3, 5-6). For the analysis of the association between psychological characteristics and their help-seeking behaviour (aim 4), a power analysis was performed for two exposures – education and marital status. In a study by Whitaker et al. it was reported who was most likely to seek help in the past 3 months when experiencing a cancer alarm symptom. Assuming that the proportion of help-seeking is 0.556 among university graduates and $\alpha=0.05$, we will be able to detect a difference of 0.049 in the proportion of being help-seeker between those with education below university and university graduates with power=0.78 (37).

Development of questionnaires

The development of questionnaires will take place in close collaboration with the research group and experts within the field. Furthermore, cancer patients and GPs will be involved in the development of the questionnaire. The development will consist of the following three steps in accordance with recommendations by Fayers et al. (38).

Step 1: Literature review

The initial step includes literature searches of relevant journals and bibliographic databases, to ensure that all relevant issues are included and to identify areas within the field which needs further investigation. Any existing instruments that addresses the same or related areas of quality of life assessment should be identified and reviewed (38).

Step 2: Item formulation

Item formulation will be done by the study's research group. The aim is to formulate items that reflect the identified themes from the literature and are understood by lay people. Streiner & Norman's guidelines will be followed while formulating the items (39). This include elimination of any items which are *ambiguous* or *incomprehensible*. Then *reading level* must be taken into account. The guidelines also states caution towards the use of a '*double-barrelled*' item, which asks two or more questions at the same time or *jargon terms*.

Step 3: Patient and GP interviews to ascertain content and face validity

Patients: *Key informant interviews* will be held with a small number of people who are chosen because of their unique knowledge (39). We select patients who have cancer for the second time, and who can articulate their impression of the questionnaire. In interviews, the patients will review the suggested items and make suggestions for further items/themes to investigate. The criterion often used in this type of research is 'sampling to redundancy'; that is, interviewing people until no new themes emerge (39).

GPs: Also *key informant interviews* will be held with GPs, who will be asked to comment on the items. It is important that they are convinced of the quality of the items.

The patient questionnaire will contain questions on:

- Experienced symptoms (if any)
- Route to diagnosis of cancer recurrence (e.g. follow-up or symptom presentation to GP/hospital)
- Patient's confidence in the GP's handling of symptoms
- Patient's evaluation of other professional's medical advice (e.g. from oncologists)
- Length of time intervals (e.g. patient interval and GP interval)
- Fear of recurrence and fatalism

The GP questionnaire will contain questions on:

- GP's involvement in the detection of cancer recurrence
- GP's interpretation of the patient's symptoms
- Whether the GP suspected cancer recurrence and the handling of such suspicion (including diagnostic activities within the general practice setting)
- Length of the diagnostic time interval
- GP's confidence in own ability to provide care for cancer patients in remission (e.g. symptom recognition, evaluation of collaboration between the GPs and e.g. the Department of Oncology).

Validity and data security

All collected data will be stored via the CaP project database hosted by Statistics Denmark. Besides the collected questionnaire data, it will be possible to link data to a range of Danish national registries, which all have continuously updated and almost complete records. This will ensure data of high validity (9,40-42).

This project will draw on the experiences from former studies conducted by CaP researchers (32,34-36,43) to ensure a feasible and high-quality project. Based on previous studies from CaP, we expect a response rate of approximately 80-85% for the GP questionnaire (32). Selection bias cannot be entirely avoided as some patients will be too ill to participate or will have died before the questionnaire is sent out.

Additionally, lower response rates have been observed among people with lower socioeconomic status, which can also threaten the validity of the study. On the basis of previous projects, we expect to obtain a response rate of approximately 50-60% among the patients (32).

Recall bias may challenge the validity of the findings. As patients are identified after the diagnosis of cancer recurrence, they will be asked to retrospectively report their symptom experience and key dates. This might affect the answers, specifically among patients who – in hindsight - did not act promptly on their symptoms. This project will include Danish national high-quality registries to identify cancer recurrence cases; this will ensure complete coverage.

Project group and time plan

This postdoctoral project will be conducted by Marie Germund Nielsen between 1 January 2018 and 1 January 2020. The first year is dedicated to develop and validate patient and GP questionnaires. The second year is dedicated to data collection, initial data processing and data analysis. Associate professor Anette Fischer Pedersen will provide support on expertise in psychological aspects of the study. The project group further includes Professor Peter Vedsted (will provide support on various aspects of the study), postdoctoral fellow Line Flytkjær Virgilsen (expertise in epidemiology and questionnaire surveys), postdoctoral fellow Henry Jensen (expertise in questionnaire survey and national registries), professor and GP Frede Olesen (expertise in the healthcare system in general) and statistician Alina Zalounina Falborg (expertise in statistical issues).

Ethical considerations

Although this project does not involve biomedical intervention, the project will be reported to the Regional Committee on Health Research Ethics in the Central Denmark Region prior to initiation. This project has been approved by the Danish Data Protection Agency (j.no. 2015-41-4217). Precise identification of patients with cancer recurrence is crucial to avoid sending questionnaires to cancer survivors without cancer recurrence. CaP will ensure such precise identification by validating register data (as part of the formerly mentioned PhD project).

Budget

The project will be co-financed by resources from CaP, which forms part of the Research Unit for General Practice, Aarhus University. CaP will co-finance salaries for the project administrator, the collaborators in the project group, language revision of scientific papers, publication fees and costs of office premises. The project will also be co-financed by a grant from the Danish Health Foundation, which will partly fund the salary for postdoctoral fellow Marie Germund Nielsen.

We will apply to the Danish Cancer Society for the remaining part of the salary for Marie Germund Nielsen as well as salary for a data manager and a statistician. Please see budget for further details.

Publications and dissemination

The results will be presented at national and international conferences and communicated to the press. At least six peer-reviewed scientific papers will be published in international journals; four papers with Marie Germund Nielsen as the first author and two papers with another project member as first author:

- 1) Routes to diagnosis of patients with cancer recurrence.
- 2) Symptom presentation in general practice among patients with cancer recurrence.
- 3) Time intervals from first symptom to diagnosis among patients with cancer recurrence.
- 4) GP suspicion of cancer recurrence in the aftercare for cancer survivors.
- 5) Diagnostics and follow-up of cancer survivors: the GP's perspective.
- 6) Associations between psychosocial characteristics and help-seeking behaviour in patients with cancer recurrence.

- (1) National Board of Health. Cancerregistry [in Danish: Cancerregisteret 2010]. Version: 1.0; Versiondato: December 2011 ed. Copenhagen; 2011.
- (2) Baker F, Denniston M, Smith T, West MM. Adult cancer survivors: how are they faring? *Cancer* 2005 Dec 1;104(11 Suppl):2565-2576.
- (3) Pedersen AF, Rossen P, Olesen F, von der Maase H, Vedsted P. Fear of recurrence and causal attributions in long-term survivors of testicular cancer. *Psychooncology* 2012 Nov;21(11):1222-1228.
- (4) Grunfeld E, Mant D, Yudkin P, Adewuyi-Dalton R, Cole D, Stewart J, et al. Routine follow up of breast cancer in primary care: randomised trial. *BMJ* 1996 Sep 14;313(7058):665-669.
- (5) Ellegaard MB, Grau C, Zachariae R, Bonde Jensen A. Fear of cancer recurrence and unmet needs among breast cancer survivors in the first five years. A cross-sectional study. *Acta Oncol* 2017 02/01;56(2):314-320.
- (6) Grunfeld E. Cancer survivorship: a challenge for primary care physicians. *Br J Gen Pract* 2005 Oct 1;55(519):741-742.
- (7) Tsianakas V, Maben J, Wiseman T, Robert G, Richardson A, Madden P, et al. Using patients' experiences to identify priorities for quality improvement in breast cancer care: patient narratives, surveys or both? *BMC Health Serv Res* 2012;12:271-6963-12-271.
- (8) American Cancer Society. When Cancer Comes Back: Cancer Recurrence. 2015;1(1).
- (9) Lash TL, Riis AH, Ostfeld EB, Erichsen R, Vyberg M, Thorlacius-Ussing O. A validated algorithm to ascertain colorectal cancer recurrence using registry resources in Denmark. *Int J Cancer* 2015 May 1;136(9):2210-2215.
- (10) Galandiuk S, Wieand HS, Moertel CG, Cha SS, Fitzgibbons RJ, Jr, Pemberton JH, et al. Patterns of recurrence after curative resection of carcinoma of the colon and rectum. *Surg Gynecol Obstet* 1992 Jan;174(1):27-32.
- (11) Cali RL, Pitsch RM, Thorson AG, Watson P, Tapia P, Blatchford GJ, et al. Cumulative incidence of metachronous colorectal cancer. *Dis Colon Rectum* 1993 Apr;36(4):388-393.
- (12) Hassett MJ, Ritzwoller DP, Taback N, Carroll N, Cronin AM, Ting GV, et al. Validating billing/encounter codes as indicators of lung, colorectal, breast, and prostate cancer recurrence using 2 large contemporary cohorts. *Med Care* 2014 Oct;52(10):e65-73.
- (13) Armstrong DK. Relapsed ovarian cancer: challenges and management strategies for a chronic disease. *Oncologist* 2002;7 Suppl 5:20-28.
- (14) Soerjomataram I, Coebergh JW. Epidemiology of multiple primary cancers. *Methods Mol Biol* 2009;471:85-105.
- (15) Israel O, Kuten A. Early detection of cancer recurrence: 18F-FDG PET/CT can make a difference in diagnosis and patient care. *J Nucl Med* 2007 Jan;48 Suppl 1:28S-35S.
- (16) Brennan ME, Gormally JF, Butow P, Boyle FM, Spillane AJ. Survivorship care plans in cancer: a systematic review of care plan outcomes. *Br J Cancer* 2014 Nov 11;111(10):1899-1908.

- (17) Smith IE, Schiavon G. Follow-up tests to detect recurrent disease: patient's reassurance or medical need? *Breast* 2013 Aug;22 Suppl 2:S156-60.
- (18) Danish Health Authority [Sundhedsstyrelsen]. Follow-up programs for cancer diseases [Opfølgningsprogrammer for kræftsygdomme]. Available at: <https://www.sst.dk/da/sygdom-og-behandling/kraeft/opfoelgningsprogrammer>. Accessed 05/22, 2017.
- (19) Danish Health Authority [Sundhedsstyrelsen]. Follow-up program for gynecological cancers [Opfølgningsprogram for gynækologiske kræftformer]. Professional advice 2015;1(1).
- (20) Pedersen AF, Rossen P, Vedsted P. Oncology and general practice: On communication and collaboration between oncologists and general practitioners [Onkologi og almen praksis: Om kommunikation og samarbejde mellem onkologer og alment praktiserende læger]. the monthly periodical for Danish general practitioners [Månedsskrift for Almen Praksis] 2017;1(January):71-79.
- (21) Easley J, Miedema B, O'Brien M, Carroll J, Manca D, Webster F, et al. The role of family physicians in cancer care: perspectives of primary and specialty care providers. *Curr Oncol* 2017 Apr;24(2):75-80.
- (22) Grunfeld E, Mant D, Yudkin P, Adewuyi-Dalton R, Cole D, Stewart J, et al. Routine follow up of breast cancer in primary care: randomised trial. *BMJ* 1996 Sep 14;313(7058):665-669.
- (23) Duineveld LAM, van Asselt KM, Bemelman WA, Smits AB, Tanis PJ, van Weert HCPM, et al. Symptomatic and Asymptomatic Colon Cancer Recurrence: A Multicenter Cohort Study. 2016;14:215-220.
- (24) Von Georgi R, Schubert K, Grant P, Munstedt K. Post-therapy surveillance and after-care in ovarian cancer. *Eur J Obstet Gynecol Reprod Biol* 2004 Jun 15;114(2):228-233.
- (25) National Board of Health [Sundhedsstyrelsen]. Control for gynecological cancer patients: a medical technology assessment [Kontrolforløb for gynækologiske kræftpatienter : en medicinsk teknologivurdering]. 2009.
- (26) Foster C, Wright D, Hill H, Hopkinson J, Roffe L. Psychosocial implications of living 5 years or more following a cancer diagnosis: a systematic review of the research evidence. *Eur J Cancer Care (Engl)* 2009 May;18(3):223-247.
- (27) Alter CL, Pelcovitz D, Axelrod A, Goldenberg B, Harris H, Meyers B, et al. Identification of PTSD in cancer survivors. *Psychosomatics* 1996 Mar-Apr;37(2):137-143.
- (28) Fidjeland HL, Brekke M, Vistad I. General practitioners' attitudes toward follow-up after cancer treatment: A cross-sectional questionnaire study. *Scand J Prim Health Care* 2015 Dec;33(4):223-232.
- (29) Del Giudice ME, Grunfeld E, Harvey BJ, Pilotis E, Verma S. Primary care physicians' views of routine follow-up care of cancer survivors. *J Clin Oncol* 2009 Jul 10;27(20):3338-3345.
- (30) Sandager M, Sperling C, Jensen H, Vinter MM, Knudsen JL. Danish cancer patients' perspective on health care: results from a national survey. *Cognition, Technology & Work* 2015 02/01;17(1):35-44.
- (31) National Cancer Survivorship Resource Center, Expert Panel Summit Workgroup Overview. Systems policy and practice: Clinical survivorship Care. 2014.

- (32) Jensen H, Topping ML, Larsen MB, Vedsted P. Existing data sources for clinical epidemiology: Danish Cancer in Primary Care cohort. *Clin Epidemiol* 2014 Jul 17;6:237-246.
- (33) Hansen RP, Olesen F, Sorensen HT, Sokolowski I, Sondergaard J. Socioeconomic patient characteristics predict delay in cancer diagnosis: a Danish cohort study. *BMC Health Serv Res* 2008 Feb 28;8:49-6963-8-49.
- (34) Jensen H, Topping ML, Olesen F, Overgaard J, Fenger-Gron M, Vedsted P. Diagnostic intervals before and after implementation of cancer patient pathways - a GP survey and registry based comparison of three cohorts of cancer patients. *BMC Cancer* 2015 Apr 23;15:308-015-1317-7.
- (35) Pedersen AF, Olesen F, Hansen RP, Zachariae R, Vedsted P. Social support, gender and patient delay. *Br J Cancer* 2011 Apr 12;104(8):1249-1255.
- (36) Pedersen AF, Olesen F, Hansen RP, Zachariae R, Vedsted P. Coping strategies and patient delay in patients with cancer. *J Psychosoc Oncol* 2013;31(2):204-218.
- (37) Whitaker K,L., Smith CF, Winstanley K, Wardle J. What prompts help-seeking for cancer 'alarm' symptoms? A primary care based survey. *Br J Cancer* 2016 02/02;114(3):334-339.
- (38) Fayers PM, Machin D. *Quality of Life - The assessment, analysis and reporting of patient-reported outcomes*. 3rd ed. Chichester, UK: Wiley-Blackwell; 2016.
- (39) Streiner DL, Norman GR. *Health measurement scales: a practical guide to their development and use*. Fourth ed. USA New York: Oxford University Press; 2008.
- (40) Smidth M, Sokolowski I, Kaersvang L, Vedsted P. Developing an algorithm to identify people with Chronic Obstructive Pulmonary Disease (COPD) using administrative data. *BMC Med Inform Decis Mak* 2012 May 22;12:38-6947-12-38.
- (41) Erichsen R, Lash TL, Hamilton-Dutoit SJ, Bjerregaard B, Vyberg M, Pedersen L. Existing data sources for clinical epidemiology: The Danish National Pathology Registry and Data Bank. *Clinical Epidemiology* 2010 2010;2(1):51-56.
- (42) Andersen JS, Olivarius Nde F, Krasnik A. The Danish National Health Service Register. *Scand J Public Health* 2011 Jul;39(7 Suppl):34-37.
- (43) Hansen RP, Olesen F, Sorensen HT, Sokolowski I, Sondergaard J. Socioeconomic patient characteristics predict delay in cancer diagnosis: a Danish cohort study. *BMC Health Serv Res* 2008 Feb 28;8:49-6963-8-49.

Budget: The diagnosis of cancer recurrence: Patients' experiences and the role of general practice									
		Måneder	Totalbudget	Søges fra KEU Region Midtjylland	Søges fra Multipraksisud valget	Bevilget fra Helsefonden	Bidrag fra Forskningsenheden/CaP (egenfinansiering)	Bidrag søges fra Kræftens bekæmpelse	Bidrag søges fra Praksisforskningsfonden
2018	VIP	Postdoc (spørgeskema)	12	552.000,00					
		Anette Fischer Pedersen (1)	2	97.000,00			97.000,00	152.000,00	200.000,00
		Line Flytkjær Virgilsen (1)	2	97.000,00			97.000,00		
	TAP	Peter Vedsted (2)	1	73.000,00			73.000,00		
		Løn, Datamanager (3)	1	47.000,00				47.000,00	
		Løn, Stastistiker	1	47.000,00				47.000,00	
	Drift	Løn, sekretær (4)	1	40.500,00			40.500,00		
		Registerudtræk		50.000,00					50.000,00
		Print, kuverter og porto		20.500,00					20.500,00
	Pakning, kodning og scanning	Trykning af spørgeskema (4,10 kr * 5000)		80.000,00					80.000,00
		Porto udsendelse af spørgeskemaer (patienter)		5.000,00					5.000,00
		Konvolutter udsendelse af spørgeskemaer (5)		2.500,00					2.500,00
		Reminders spørgeskemaer (patienter)		80.000,00					80.000,00
		Porto besvarelse (patienter) (6)		4.100,00					4.100,00
		Trykning af spørgeskema (læger) (4.10 kr * 2800) (7)		44.800,00					44.800,00
		Porto udsendelse af spørgeskemaer (læger)		2.800,00					2.800,00
		Konvolutter udsendelse af spørgeskemaer (5)		1.400,00					1.400,00
		Reminders spørgeskemaer (læger)		44.800,00					44.800,00
		Porto besvarelse (læger)		6.500,00					6.500,00
		Pakning af patientspørgeskemaer og følgebrev (50 timer) (8)		9.750,00					9.750,00
		Kodning af returnerede lægespørgeskemaer (75 timer) (9)		19.500,00					19.500,00
		Scanning og verificering (150 timer) (10)		3.640,00					3.640,00
		Pakning af lægespørgeskemaer og følgebrev (28 timer) (8)		7.280,00					7.280,00
		Kodning af returnerede lægespørgeskemaer (56 timer) (9)		14.560,00					14.560,00
	Generelt	Scanning og verificering (112 timer) (10)		20.000,00			20.000,00		
		Konferencer/formidling		16.000,00			16.000,00		
		Sprogrevision (4 artikler)		40.000,00			40.000,00		
		Publiceringsafgift (4 artikler)		5.000,00			5.000,00		
		Kursusudgifter og bøger		595.800,00	74.475,00	595.800,00			
		Honerering af praktiserende læger (11) (12)		10.000,00			10.000,00		
		Computer hard og software		60.000,00			60.000,00		
		Driftsbidrag til forskningsenheden		2.097.430,00	595.800,00	200.000,00	458.500,00	246.000,00	597.130,00
		I alt 2017							
2019	VIP	Postdoc (spørgeskema)	12	563.040,00				563.040,00	
		Anette Fischer Pedersen (1)	2	98.940,00			98.940,00		
		Line Flytkjær Virgilsen (1)	2	98.940,00			98.940,00		
	TAP	Peter Vedsted (2)	1	74.460,00			74.460,00		
		Løn, Datamanager (3)	1	47.940,00				47.940,00	
		Løn, Stastistiker		47.940,00				47.940,00	
	Drift	Løn, Sekretær (4)	1	41.310,00			41.310,00		
		Konferencer/formidling		20.000,00			20.000,00		
		Sprogrevision (2 artikler)		8.000,00			8.000,00		
	Generelt	Publiceringsafgift (2 artikler)		20.000,00			20.000,00		
		Kursusudgifter og bøger		5.000,00			5.000,00		
		Driftsbidrag til forskningsenheden		60.000,00			60.000,00		
		I alt 2018		1.085.570,00		-	426.650,00	658.920,00	597.130,00
		Direkte omkostninger i alt		3.183.000,00	595.800,00	200.000,00	885.150,00	904.920,00	
	Administrationsgebyr inkl. barsel 6% (13)			190.980,00	35.748,00	12.000,00	107.404,20	-	
		I alt		3.373.980,00	74.475,00	631.548,00	992.554,20	904.920,00	597.130,00

(1) Beløbet inkluderer nettoløn, pensionsbidrag, lønbidrag, særlig feriegodtgørelse og feriepenge samt 2% årlig lønstigning.

(2) Medfinansieret løn til professor Peter Vedsted

(3) Løn til datamanager er løn for 2017: 47.000 pr mdr. inkl. lønregulering på 2% pr. år. Der er medregnet feriepenge i sidste år.

(4) Løn til sekretær er løn for 2017: 40.500 kr pr. mdr inkl. lønregulering på 2% pr. år. Der er medregnet feriepenge i sidste år.

(5) Der benyttes to kuverter pr. udsendte spørgeskema: 1 til udsendelse af spørgeskemaet og 1 til returnering af spørgeskemaet.

(6) Ved en svarprocent på 75%.

(7) Ud af de ca. 5.000 patienter der modtager et spørgeskema, har vi estimeret, at ca. 3.000 patienter giver samtykke til, at vi må kontakte deres alment praktiserende læge.

(8) Pakning og udsendelse: 100 skemaer/time af studentermedhjælper. 130 kr i timen.

(9) Kodning af 5000 patientspørgeskemaer og 2250 lægespørgeskemaer: 50 skemaer/time af studentermedhjælper. 130 kr i timen.

(10) Scanning og verificering: 25 skemaer/time af studentermedhjælper. 130 kr i timen.

(11) Vi forventer at udsende spørgeskemaet til 375 læger i Region Midtjylland og forventer en svarprocent på 75%, dvs. 281 læger besvare spørgeskemaet. Lægerne skal honoreres for 2 x 10 minutter, svarende til 264,80 kr. Dvs. 74475 Kr.

På landsplan forventer vi at udsende spørgeskemaer til 3000 læger, der er 375 praktiserende læger i Region Midtjylland.

(12) Administrationsgebyr på 6% af evt. bevilling fra KB dækkes af Forskningsenheden/CaP