

## Online Information about Cancer Patient Pathways (CPP) in Norway

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**Abstract**—A Cancer Patient Pathways (CPP)- program was implemented in Norway in January 2015. An important emphasis of CPP is that the patient should be ensured adequate information and involvement in relation to her/his cancer diagnosis and treatment. Updated information about CPPs in Norway is mainly available through two Web portals: [helsedirektoratet.no](http://helsedirektoratet.no) and [helsenorge.no](http://helsenorge.no). With reference to Critical Discourse Analysis and Fairclough's notions *knowledge exchange* and *activity exchange*, the online information about CPP is examined and discussed with an emphasis on what characterizes the communication exchange. The results show that the CPP online information has an unclear addressee, and that there is more activity exchange with directives to health personnel than knowledge exchange with health facts to patients on both health portals. The conclusion is that in order to develop targeted and adequate online information, health authorities need to be aware of citizens' eHealth literacy.

**Keywords**- cancer patient pathways; CPP, critical discourse analysis; CDA; communication exchange; knowledge exchange; activity exchange; the ADIUVAT-model.

### I. INTRODUCTION

The research-based knowledge about of how eHealth will influence healthcare delivery is limited. The potential of using eHealth services for health information exchange seems promising, since a large group of people can be reached efficiently. However, there are important issues to take into consideration when eHealth is adopted in healthcare, one of them being the digital divide [1]. Although eHealth has become widely available, accessible and affordable, there is a cultural and social gap between those who use the eHealth services and those who do not. This divide, caused, for example, by a lack of infrastructure, computer equipment, motivations or skills, affects the society on an overall level. Even more importantly, the eHealth literacy level of the citizens varies [2] [3] [4] [5] [6]. While some are perfectly able to understand and apply the information given, others are to be considered illiterate. We should acknowledge that these mechanisms also might have unintentional consequences within health. The problems related to the eHealth divide should therefore be taken into account in the communication and information distributed to patients of all diagnostic categories.

Healthcare authorities and healthcare institutions are responsible for providing health information relevant to the healthcare services they offer to the population and the patients. But what characterizes health information? How can we distinguish good quality health information from bad quality health information? The objective of this paper is to examine certain aspects of health information provided from health authorities and health institutions concerning cancer patient pathways (CPP). It is especially interesting to analyze how existing information is presented and to whom. The following research question guides the paper: *What characterizes the online information from the authorities concerning the cancer patient pathways in Norway?*

The expected outcome of this paper is threefold: 1) knowledge about the discursive characteristics of the online information about CPP from the Norwegian authorities available for health personnel and for patients and their caregivers, 2) a discussion of notions from Critical Discourse Analysis as tools for analysing online health information in general, 3) a model of the patients health information pathway. The subsequent part of Section I offers an introduction to the CPP program in Norway. Section II presents the theoretical and analytical framework of the paper, while Section III is the methodology section. Section IV offers the analysis and results, and these are discussed in Section V, where the ADIUVAT-model is also suggested. Section VI contains concluding remarks.

#### *A. The introduction of Cancer Patient Pathways in Norway.*

Inspired by Denmark, the Norwegian Government introduced Cancer Patient Pathways (CPP) (Norwegian: "pakkeforløp for kreft") in January 2015. The politically decided introduction of 28 CPPs is expected to have an impact on logistics and on information flow in patient care. The purpose of the CPPs is that "cancer patients will experience a well-organized, coherent and predictable pathway without unnecessary, non-medically justified delays in assessment, diagnosis, treatment and rehabilitation. An important aspect is that patients must be ensured adequate information and involvement." [7] [8] The Directorate for Health emphasizes that it is a logistics reform, and not new guidelines for diagnosis [9].

After 12 months of iterative implementation of 28 CPP and 31 diagnostic guidelines in primary and specialist healthcare, the overall experience is positive; the pathway is more predictable for the patients and their next-of-kins [9]. However, some issues are raised that indicate that there is still room for improvement. One issue is that patients are more focused on time, and tend to have time as a driving force in their communication with healthcare. However, the CPP does not reduce medically justified delays. Moreover, experiences show that the bottlenecks in the CPP are imaging, endoscopy, and pathology. This is in coherence with the findings in Denmark [10]. This challenge calls for a structural change in the respective departments as well as a focus on communication across departments and towards patients. Moreover, the transition between primary and specialist healthcare is challenging, for example with regard to the quality of referrals from the general practitioners. Previously the GPs wrote a thorough description, whereas now many write only “pakke” (package). Also, the lack of coordinated data systems poses challenges. The use of contract specialists and private actors makes routines and information flow challenging due to different systems. The procedures of coding are challenging for both doctors and health secretaries due to different patient administration systems. Moreover, the preparation of reports to aid in improvement work is not yet initiated. Yet another issue is the coordination of the pathway for the patient. The role of the pathway coordinators is regarded as important. However, experiences show that the teaching and training of pathway coordinators and the definitions of their tasks are not adequately established. Finally, there is a challenge with regard to management, economy and redistribution of resources since the government has not allocated more financial support for the implementation of the reform.

The glue in the logistical chain of the CPP is communication and information flow. The Directorate of Health [7] emphasizes the importance of involving the patient and next-of-kin in decision-making throughout the pathway. The patient is given the *promise*, and the *right*, to be involved actively in the decision-making about own health. Moreover, ethics in the communication i.e. “respect and empathy, shall be maintained“. In addition, the Directorate of Health emphasizes that social aspects, expectations and the “individual abilities” of the patient shall be taken into consideration, and the pathway shall be predictable at all stages. The promise, and right, to be involved in decision-making, to be treated ethically, to be addressed according to the individual health- and eHealth literacy level and to experience a predictable pathway demonstrates a good intention from the authorities about patient-centeredness in healthcare. But what are the implications of including patients in decision-making about their own health? Decision-making is the situation where a choice is made among many possible choice alternatives. The task of making decisions about his/her own health

based on assessments of different alternatives requires an understanding of what we can expect from the healthcare system, and what kind of information is available at what time during the patient pathway.

Inclusion of patients can be done through mainly two ways of communication and information exchange. Firstly, through face-to-face communication where the specific condition of the patient is discussed and followed in iterative consultations, and secondly, through making information available in a written form for patients to consult to obtain knowledge about the condition in general as well as with regard to the condition of the specific patient. Subsequently, the online information available about CPP in Norway is discussed in relation to analytic notions from Critical Discourse Analysis.

## II. THE THEORETICAL AND ANALYTIC FRAMEWORK

### A. Discourse Analysis

The theoretical and analytic framework for this project is Discourse analysis. Discourse analysis is a perspective on social life that contains both methodological and conceptual elements [11]. There are various approaches to discourse analysis depending on the object of study. This paper draws on notions from Critical Discourse Analysis (CDA) [12].

According to Fairclough [12], discourse analysis is based on the assumption that language is an irreducible part of social life, dialectically interconnected with other elements of social life, so that social analysis and research always has to take account of language. Social life can, and should, be studied through a focus on language. CDA is concerned with continuity and change at a structural level in society as well as at a more narrow textual level. In this paper the focus is on a textual level, with the point of departure that texts are produced to bring changes in society, for example in healthcare, education, politics and trade.

In the analysis of the online information about CPP we make a distinction between two types of exchange in communication: *Knowledge exchange*, that has a focus on exchange of information, making claims, stating facts, and *activity exchange*, that has a focus on activity, on people doing things or getting people to do things (12). Based on this distinction, we analyse online information about CPP with the help of *speech functions* (for example instructions, solicitations, statements, questions, demands and offers), and look at what kind on sentence types are appearing (for example interrogative, and imperative sentences). The generalized speech functions can again be distinguished into speech acts. The speech function “Offer” could for example include the speech acts promising, threatening and thanking, while the speech function “Demand” would include for example the speech acts ordering and requesting.

### III. METHODOLOGY

A keyword search on “pakkeforløp” and “pakkeforløp for kreft” was conducted. A list of hospitals, regional health authorities, interest organisations and “other” linked to the keyword appeared. The links were systematically examined, and the content described. Also external links were mapped. The majority of the institutions mentioned had brief information about CPP, but linked to the Webpages provided by the Directorate of Health for more information. Some hospitals had developed their own information on CPP, with overviews of CPP coordinators, leaders and timeframes for each cancer type. Since the Web portals from the Directorate of Health were linked to from most institutions, there are expectations at hospitals all over the country that the Directorate of Health should provide adequate information about CPP. This is the reason why we decided to study the content on CPP available at [helsedirektoratet.no](http://helsedirektoratet.no) and [helsenorge.no](http://helsenorge.no) more closely. In this paper, the following data is studied: CPP online information provided by the Directorate of Health including: 1) Information at the health portal [helsedirektoratet.no](http://helsedirektoratet.no) [13] and 2) Information at the health portal [helsenorge.no](http://helsenorge.no) [7]. Selected sections are studied in depth, and analyzed in a CDA perspective.

### IV. ANALYSIS

#### A. Information about CPP in Norway available online

The online information is examined theoretically and analytically through drawing on the following notions from CDA; 1) addresser and addressee, and 2) knowledge exchange versus activity exchange.

#### B. Addresser and addressee

The primary addresser of both [helsedirektoratet.no](http://helsedirektoratet.no) and [helsenorge.no](http://helsenorge.no) is the Directorate of Health.

[Helsedirektoratet.no](http://Helsedirektoratet.no) information concerning CPP has a double addressee: first, GPs, healthcare professionals in primary- and specialist healthcare, and secondly, patients. The information for healthcare professionals as primary addressee is for example the contact information emphasizing that the GP and other healthcare professionals can contact the Directorate via email address if they have questions. In addition, topics of the Website are diagnostic guidelines and the role of the CCP coordinator. On the same page, there is a link called “CPP and patient information”. The primary addressee is the healthcare professional who can subsequently advise the patient to access it herself/himself.

The primary addressee at [helsenorge.no](http://helsenorge.no) is the patient. [Helsenorge.no](http://Helsenorge.no) is a health portal, and the idea is to gather information relevant for the patients (for example general health information, booking appointments, electronic health record at hospitals (pilot in two regions), ePrescriptions,

referrals, deductibles, summary care record/ kjernejournal). The information about CPP is found under the categories diagnosis/cancer/ CPP (updated 30.08.2015).

In the subsequent section we analyze the online health information on CPP in two cases, respectively: Case 1: assessment of selected CPP information at [helsedirektoratet.no](http://helsedirektoratet.no) and Case 2 assessment of selected CPP information at [helsenorge.no](http://helsenorge.no).

#### C. Case 1: [helsedirektoratet.no](http://helsedirektoratet.no)

The information on the Web portal [helsedirektoratet.no](http://helsedirektoratet.no) concerning CPP is organized in the following main categories: 1) Aim of CPP, 2) CPP and patient information, 3) Diagnostic guidelines- the role of the general practitioner (GP), 4) Implementation of CPP, 5) Experiences from Denmark and 6) Code Guidelines.

Category 2), “CPP and patient information”, links to “general information for all CPPs”, which is the same information as presented in the Action Plan and “general patient information about examination for suspected cancer”. In addition, “CPP and patient information”, links to information about all 28 types of cancer included in the CPP program. The information on each cancer type is organized with a) an introduction to the specific type of cancer, b) the entrance to the CPP (risk groups, symptoms, referral to CPP, decision about CPP, information and dialogue with the patient, responsibility for the referral, registrations, pathway times, c) examination about the cancer type, d) initial treatment, e) follow-up and control, pathway times, e) registrations of codes in the CPP (codes to be used at examination, at biopsy, at transferal to another hospital, at decision about initial treatment, at treatment, at the end of the CPP). With reference to the analytic categories of Fairclough [12], in the subsequent section we do an analysis of the communication exchange in category 2) “CPP and patient information”.

#### a) Lung cancer as an illustrative example

All information about the 28 cancer types is structured similarly, so the information about lung cancer is used as an illustrative example [14]. The link: “The introduction to CPP for lung cancer” leads to the section on “General information about lung cancer” which contains a brief *knowledge exchange*, as manifest in for example the following two sentences with *statement of facts*: “Annually around 2,900 are diagnosed with lung cancer. In 2012 respectively 1,600 men and 1,300 women were diagnosed.” The factual statements are followed by an *evaluation* “The prognosis is not good”, with a support of a new *factual statement*: “Five years of relative survival is 19 % for women and 13 % for men”. This worrying reading is tentatively *modified by a new statement of fact*: “Modern treatment resulted in somewhat better prognosis than previously”. The next section “National action program” is brief, and links to an action plan (broken link).

The subsequent section, “Pathway coordination” refers to the coordination of the pathway. The main kind of communication exchange here is *activity exchange*, as exemplified in: “Coordination of the patient pathway shall ensure effective pathways from the time the referral is received by specialist health service until treatment is started or CPP is concluded, without undue delay and with close cooperation between all involved departments and specialists.” This *instruction*, from the Directorate of Health to all departments and specialists, gives directions about how to proceed with CPP effectively and within an expected timeframe. Subsequently, a new *instruction* is given, this time specifically about how hospitals are expected to coordinate the pathway: “All hospitals that investigate and treat cancer should have course coordinators who have close contact with the patient and involved agencies.” This is followed by an *instruction* on who shall be in charge of the particular CPP: “Pulmonary Physician will be the one that formally starts CPP for lung cancer, and has a central role in coordination with other specialists.” The two latter *instructions* concern roles and responsibilities professionally, and within and across institutions.

Also in the section “Multidisciplinary teams”, the *activity exchange* is the primary communication exchange mode, “All hospitals that treat lung cancer shall have regular multidisciplinary decision-making meetings. At meetings where lung surgery is considered, the lung specialist, the thorax surgeon, the oncologist, the radiologist, the pathologist, the nuclear medicine specialist and the pathway coordinator should participate”. This demonstrates an *expectation* from the Directorate of Health about how the respective hospitals should organize decision-making and who are expected to participate. This requires thorough coordination of clinical personnel, and puts demands on their priorities. Interestingly, the patient is not mentioned. This is followed by a *knowledge exchange* formulated as an *evaluation*: “These meetings ensure quality control of diagnosis and surgical treatment as well as planning of further treatment.”

The section “Information and dialogue with the patient” is also characterized by *activity exchange*, but is to a lesser extent dominated by instructions and more characterized by underlying *values* from the addresser as to how information *should* be conveyed. Fairclough [12] claims that there is a value-content in factual statements that links knowledge exchange to activity exchange. When promoting information and dialogue with the patient as an important tool in the CPP, the Directorate of Health expresses the objective that patients and next-of kins should experience good information, involvement, influence and dialogue throughout the pathway. In an *activity exchange*, the inclusion of the patient is not formulated as an instruction, but a *solicitation*, expressed in present tense: “The patient and the responsible doctor jointly decide the further pathway”. However, the expectation about the patients being treated with respect and empathy is an *instruction*:

“The communication with the patients and their families *shall* in all circumstances be based on respect and empathy. Information and dialogue should take place in a considerate way and be adapted to the recipient’s individual abilities such as age, social situation, language, expressed wishes and needs.” This instruction contains value-content about how patient communication is best conducted, but does not really specify what respect and empathy actually means in the context. However, subsequently we read a *value-content solicitation* about an aspect that the healthcare professional should emphasize in the communication, namely the patients expectations throughout the pathway: “Further, the communication with the patient *should* include a clarification concerning expectations about the pathway, including inclusion of patient and next-of kin”. Note that the difference between the tense of the use of the verb *shall* and *should* also indicates the difference between instruction and solicitation here.

Finally, there are *instructions* about how communication and information should be: «Communication and information shall be consistent and coordinated. As part of the communication, the patient and next-of-kin shall iteratively be involved and informed about examination results and next step in the CPP.” The addressee of this instruction is seemingly the coordinator since she is the one that is appointed to have all coordination and overall contact with the patient. The subsequent *instruction* is giving directions to the hospital managements about how they should organize for good communication: “The hospitals shall, in cooperation with relevant patient organizations, prepare for talks with authorized peers if the cancer patients and/or the next-of-kins wish this.” The Directorate has *expectations* about information and dialogue that accompanies the implementation of CPP, but with unspecified criteria.

#### D. Case 2: helsenorge.no

The information online about CPP offered on the patient health portal helsenorge.no is introduced with a section concerning the goals of the CPP, i.e. that patients should experience a complete and predictable pathway without unnecessary delays caused by non-medical factors, and that patients shall receive information and be involved.

The pathway coordinator is mentioned briefly as contact point for the patients. The patients will be informed about a telephone number to call for information. In addition, on the right side of the Website, there is a telephone number, with opening hours during daytime. The information emphasizes that the results are being good so far, for example in keeping the predefined time schedules.

Helsenorge.no information concerning CPP links to information booklets for the 28 distinct types of cancer included in the CPP-program. The booklets introduce the respective CPP for the specific type of cancer with two pages concerning the examination about cancer and the phases for examination and treatment. Examination and

treatment is illustrated in a table as illustrated in Table 1, where the expected time is particularly emphasized.

TABLE 1: ESTIMATED TIME IN EACH PHASE OF THE CPP

De forskjellige fasene i utredningen	Kommentarer	Anbefalt innen:
<b>Fase 1:</b> Dette er tiden fra sykehuset mottar henvisning til du møter i sykehus første gang	Forløpskoordinatoren sørger for å sette opp timene du skal ha i utredningen.	7 kalenderdager
<b>Fase 2:</b> Dette er tiden fra du møter i sykehuset første gang til utredningen din er ferdig	I løpet av dette tidsrommet blir det gjort undersøkelser av deg for å avklare om du har kreft eller ikke.  Ved mistanke om kreft vil du undersøkes av lege. Det tas blodprøver, beinmargsprøve og ofte ulike røntgenundersøkelser.  Når resultatene fra undersøkelsene og prøvene er klare, vil det som oftest kunne avklares om du har kreft eller ikke. Beslutning om diagnose tas. Har du ikke kreft, avsluttes pakkeforløpet.	20 kalenderdager
<b>Fase 3:</b> Dette er tiden fra det er fastslått at du har kreft og til behandlingen starter	Har du kreft, vurderes nå om du skal behandles og eventuelt hvilken behandling som er best for deg. Beslutning om dette tas i samråd med deg.  Myelomatose trenger noen ganger ikke behandling, men når behandling er aktuelt vil dette oftest være kjemoterapi, av og til med strålebehandling.	Medikamentell behandling 3 kalenderdager

All information about the CPP diagnostic categories is organized in the same way. Table 1 is an illustrative example borrowed from the booklet on myelomatosis. The table emphasizes *knowledge exchange* in *progress description* of the 3 different phases in the examination and the *estimated* time frame (in days) for each phase. The middle column contains comments. The first comment, “The pathway coordinator makes sure that you will undergo examinations in order to clarify if you have cancer or not”, is an example *activity exchange* with a third party actor, the coordinator. The primary addressee is the patient. However, the indirect addressee here is the coordinator and the healthcare institution that has the responsibility to provide for this service.

The comments concerning phase 2, can be interpreted as a mix between knowledge exchange and activity exchange: depending on who the addressee is: “During this time frame examinations will be done to decide whether you have cancer or not. On suspicion of cancer you are examined by a doctor. Blood tests, bone marrow tests, and different x-rays are conducted. When the results are ready, usually it is possible to decide whether you have cancer or not. If you haven’t got cancer, the CPP is terminated”. Here we can identify a primary addressee; the patient, and an indirect addressee; the institutions in charge of providing care. The progress of the process is described. This is an example that shows that the information can be regarded as *knowledge exchange* to the primary addressee, the patient, as it explains the rationale behind what is going to happen throughout the pathway. However, to the indirect addressee, the information is rather *activity exchange*, and gives instructions to the healthcare professional about the procedures throughout the CPP.

## V. DISCUSSION

We have seen that the information at both helsedirektoratet.no and helsenorge.no concerning CPP has multiple addressees; the healthcare institutions concerned with CPP, the healthcare professionals, including the management and the CPP coordinators, and the patients. At *helsedirektoratet.no*, the communication exchange about coordination, roles and responsibilities is characterized by activity exchange formulated as instructions concerning roles and responsibilities professionally and within and across institutions and expectations about multidisciplinary competencies required for professional decision-making. The communication exchange about the information with the patients is characterized by values. There are examples of instructions and solicitations containing value-content. Moreover, there are instructions and expectations about communicative responsibilities, but with unspecified criteria. At *helsenorge.no*, the knowledge exchange is characterized by the progress description and the estimation of time as factual information about the procedures in relation to the CPP. Whether the communication can be interpreted as knowledge exchange or activity exchange depends on the addressee: what can be interpreted as factual knowledge about procedures for the patient, can be interpreted as activity exchange for the healthcare professionals.

The theoretical terms from Critical Discourse Analysis *knowledge exchange* and *activity exchange* are valuable for analytically identifying what characterizes the communication exchange of online health information. The *knowledge exchange* is mainly relevant for expressing facts concerning cancer and CPP to the patients. However, from an analytic point of view, the term knowledge exchange is context-dependent, since the content interpretation may depend on who the main addressee is. The *activity exchange* is commonly used in the CPP information online, both as instructions and solicitations to the healthcare professionals and the institutions.

Online health information for the patients should be presented according to the needs of the patients at the different points in the pathway. Online information that pays attention to the heterogeneity of the patient group may be one of several measures to diminish the digital divide. Factual and targeted health information at each step of the pathway enables the patient to take part in decision-making, and make informed choices.

Health authorities that are responsible for ensuring adequate health information and communication, and consequently patients, would gain by taking the patient’s eHealth literacies, i.e. prerequisites for and capabilities to access, understand and apply online information [2][3][4][5][6], into consideration when developing health information. Especially important is the consciousness about what information and communication exchange is

relevant at what point during the pathway. Based on insights from the analysis of the CPP communication exchange, and informed by discussions on eHealth literacy (ibid), below is suggestion of a model of the patients' health information pathway. The model is called ADIUVAT (lat: helps), an acronym based on the patient's steps to finding, understanding and taking action upon the health information.

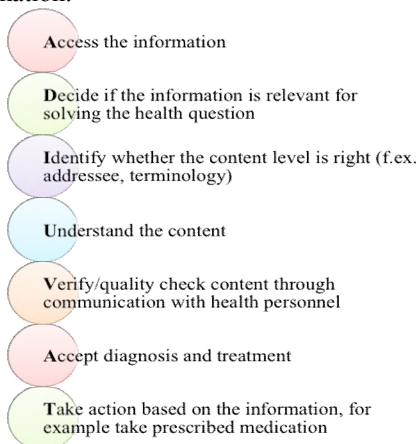


Figure 1: The ADIUVAT model

First, the citizen needs to know how to **Access** the information. After having overcome that first obstacle, the second step is to **Decide** whether the information is relevant for solving the health question or not. This requires some basic knowledge about disease and medical notions. Thirdly, the citizen must **Identify** whether the content level is right, if she/he is in the target group for the information and if the terminology is known. The fourth, and maybe the most important step, is to actually **Understand** the content. Although the citizen can understand the information on a general level, she/he will probably not fully understand the implications for her/his personal condition. Thus, as the fifth step, she may need to **Verify** and qualitycheck the content through communication with health personnel. Having understood the content in relation to diagnostic results of the personal condition, the sixth step would be to **Accept** the diagnosis and the treatment, and finally to **Take** action based on the information, for example by taking the prescribed medication. Although being under development, the ADIUVAT model may be used as a starting point for discussions about what kind of information the patients need at what point in the pathway.

## VI. CONCLUSION

The implementation of cancer patient pathways in the hospitals in Norway was a politically decided top-down process from the Norwegian authorities. The online information, which mainly consists of instructions, is perhaps a natural consequence of the top-down strategy, as it mirrors the instructions from the political leadership. Although the intentions of the Norwegian health authorities

are changes in the patient-provider relationship, moving from a paternalistic towards a more participant model, this brief analysis demonstrates that the linguistic style of the online information is rather authoritarian. The online information about CPP would benefit by having more clearly defined addressees, more knowledge exchange of facts and more clearly defined visions and criteria for what constitutes high quality health communication and information exchange. Patients, healthcare professionals and healthcare institutions would profit of an overall and explicit elaboration about the defined criteria of high quality health communication and information exchange concerning cancer patient pathways, not only with regard to online information but also in verbal communication between patients and professionals in face-to face consultations. Knowledge-based and targeted information is an important measure to reduce the digital divide.

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